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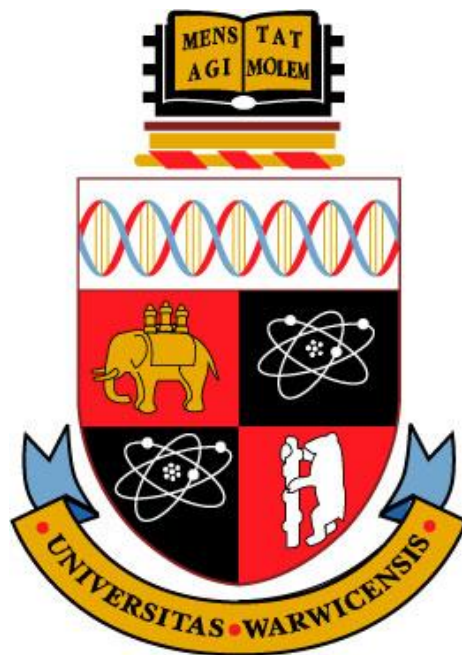
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The Vutivi study

Understanding the potential role for appropriate digital technological solutions in the innovation of health system design, implementation and normalisation in rural South Africa for both patients and health-workers:
A critical exploratory analysis



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BA. Hons (Dunelm), MSc (Oxon)

*Thesis Submitted in Fulfilment of the Requirements for the
Degree of Doctor of Philosophy in Health Science*

**University of Warwick
Warwick Medical School**

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This thesis is dedicated to
Granny Joy, Robb, Stella, Jono and Jasper
Mama Miriam and Mama Matlala



Photo 1. Mama Matlala outside of her rural home (January, 2016)

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Declaration

I, Jocelyn Olivia Todd Anstey Watkins, declare that this thesis is my own work and that it has not been submitted for any other degree at another university.

This thesis is the result of my own work. I was responsible for all data analysis. This study was solely undertaken by the author, under Warwick Medical School at **The University of Warwick**, UK, in collaboration with the Wits Centre for Health Policy and the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) in association with Department of Public Health, **University of the Witwatersrand (Wits)**, South Africa. The research was approved by both of the universities ethics committees, the Department of Health (Mpumalanga Province and Bushbuckridge sub-district) and the MRC/Wits Rural Public Health and Health and Transitions Unit.

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All photographs in this thesis are copyright to J. Watkins. Permission has been granted from all individuals in the photos to use them in this thesis. No participants feature in any of the photos and they are all people I know personally. All definitions are within the text in brackets.

There were no conflicts of interests in undertaking this research. This study is a collaboratively funded studentship by the ESRC and GE Healthcare Ltd.

Date: 10th November 2016

Signed: 



Photo 2. Mama Miriam in her kitchen on her phone

Abstract

Background: In South Africa, 81 per cent of the population are dependent on the public health system. The country faces a complex burden of a combination of chronic infectious illness and non-communicable diseases and high maternal mortality, 310 deaths per 100,000 live births. These and many other systemic health challenges have meant the government is starting to invest in digital solutions to strengthen health services delivery and public health; due to their ease of use, broad reach and wide acceptance. Digital communication systems are an intriguing possibility for delivering healthcare in low-resource settings. This thesis considers how mobile (mHealth) and non-mobile communication technologies are currently and potentially being used by patients and health-workers within the rural South African health system. Health system dimensions are also analysed at the macro-level to define the enablers and barriers to mHealth.

Methods: This qualitative exploratory study was a case study design guided by theory-driven realist methodology. Mixed-methods research triangulated in-depth individual interviews, focus group discussions, prolonged engagement in non-participant observations and documentary analysis from a diverse range of participants (community members, patients, health-workers, policy-makers and experts) operating at different tiers within the country (community, facility, district, provincial and national). A realist review of patient mobile monitoring of chronic disease was conducted to determine hypotheses to inform the interpretation of empirical data and refine theory from the Context-Mechanism-Outcome configurations. These were supported by high-level theories of access, normalisation and the capability approach.

Results: Supportive government policy combined with patient and health-workers' informal mHealth use can act as enablers to the uptake of digital communication systems, particularly with improved maintenance and management strategies. Access to health information is a barrier to care, which may be overcome with an evidence-based health website though inequities may still remain. Likewise, digital reminders may support chronic disease management particularly for patients with hypertension. Poor patient referrals and remote diagnosis can be overcome by digital communication as smartphone ownership increases and mobile data prices reduce. Local digital innovation relies on government backing for greater scale.

Conclusion: Informal digital communication solutions for health used by patients and health-workers are evident as mobile phone use becomes normalised within society. This is occurring in parallel with the government's interest in digital health technologies to strengthen the delivery of care. A novel healthcare delivery framework proposes that a foundational electronic health and mHealth ecosystem (Context) can support a health system with multiple challenges. The four health system dimensions of government stewardship, organisational, technological and financial systems are necessary to support mobile health solutions. These dimensions give reinforcement (Mechanisms) to improve communication between patients and health-workers which may increase access to healthcare and continuity of care. Work practices are made more efficient, health service delivery is enhanced and patient outcomes can improve to maximise health gain (Outcomes).

List of abbreviations and acronyms

ADHS	Attention Deficit Hyperactivity Disorder
ADSL	Asymmetric Digital Subscriber Line
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Treatment
BP	Blood Pressure
CHW	Community Health-worker
CMOc	Context-Mechanism-Outcome Configuration
DOC	Department of Communication
DOH	Department of Health
ECG	Electrocardiogram
ESRC	Economic and Social Research Council
eHealth	Electronic Health
EMS	Emergency Services
FGD	Focus Group Discussion
GSMA	Groupe Speciale Mobile Association
HDSS	Health and Demographic Surveillance Site (Agincourt)
HIV	Human Immunodeficiency Virus
HPCSA	Health Professionals Council South Africa
HPSR	Health Policy and Systems Research
ICDM	Integrated Chronic Disease Management Model
ICT	Information Communication Technology

LINC Learning, Information Dissemination and Networking with the Community

LHW Lay Health-worker

LMIC Low- and middle-income countries

mHealth Mobile Health

MDG Millennium Development Goal

MRC Medical Research Council

NCD Non-communicable Disease

NDOH National Department of Health

NHI National Health Insurance

NHS National Health Service (UK)

OPD Outpatient Department

PHC Primary Healthcare

SIM Subscriber Identity Module

SMS Short Message Service

TB Pulmonary Tuberculosis

UN United Nations

UHC Universal Health Coverage

USAID United States Agency for International Development

WHO World Health Organisation

Chapter 1



Photo 3. Mama Matlala outside her home (November, 2013)

Chapter 1: Vutivi study introduction and outline

1.1 Introduction to the Vutivi study thesis

This thesis is called the ‘Vutivi study’ (Vutivi means ‘knowledge’ in Xitsonga). It represents a large body of empirical and theoretical work. The overall aim is to understand the potential role for digital communication solutions in health systems from micro, meso and macro perspectives.

In this thesis, rural South Africa is the case study where the use of digital communication technologies within the care cycle of patients by all cadres of health-workers is examined. A particular focus is on how it is used to overcome the challenges of the ‘health system’. A health system is defined as the combination of organisations, institutions and individuals ‘directly and indirectly involved in the provision and delivery of health services to the national population’ (NDOH, 2011:5). This research focuses predominately on mobile phones and their potential to improve the performance of health systems.

Explanation of common terms used

This thesis considers digital communication systems/technologies that are mobile wireless devices, such as a phone, or non-mobile devices, such as, a networked computer.

The term mobile health (mHealth) is a sub-set of electronic health (eHealth). eHealth is defined as ‘the use of Information and Communication Technologies (ICT) for health’ (WHO, 2011:1) to support the functions and delivery of healthcare. An example of eHealth is the communication of patient data via patient electronic records. ICT includes a range of technologies, applications and services used to produce, process, distribute and transform information including telephones, mobile phones, and computers, as well as access to the Internet, social media and communication platforms (UN, 2012).

mHealth is commonly used to describe the delivery of health-related services via mobile digital communication. Kay *et al.* (2011) refer to mHealth as medical and public health practices supported by mobile devices, such as smartphones, patient-monitoring devices, personal digital assistants and tablets. The capabilities of these technologies to create, store, retrieve and transmit information between users can improve the delivery of healthcare (Akter & Ray, 2010).

Mobile devices may be used for clinical decision-support, information management to organise or deliver services, ‘assist with communication between health-workers or between health-workers and patients’, and the delivery of primary healthcare services (Odendaal *et al.*, 2015:2). Box 1

describes the South African government's categories of mHealth technologies.

Mobile devices include smartphones, patient monitoring devices, personal digital assistants and digital tablets that have functionalities, such as messaging platforms, apps, websites and social media.

Mobile digital communication can be used for the following purposes:

- Emergency response systems
- Disease surveillance and control
- Human resource co-ordination, management and supervision
- Synchronous and asynchronous mobile telemedicine diagnostic and decision-support for clinicians at point-of-care
- Remote patient monitoring and clinical care
- Health extension services, health promotion and community mobilisation
- Health services monitoring and reporting
- Health-related mobile learning for the general public
- Training and continuing professional development for health-workers

Box 1. Categories of mHealth technologies described by the South African government (NDOH, 2015a:8)

Mobile phones are being adapted to improve delivery of effective health interventions. mHealth is a way of delivering or receiving healthcare using already well-known technologies (Farrington *et al.*, 2014). Participants in this study used the words 'cell phone' to describe a 'mobile phone' and 'SMS' (Short Message Service) to describe a 'text-message'. The latter terms are more common in the literature and will be used in this thesis.

1.2 Overview of Chapter 1

Chapter 1 provides an overview of the Vutivi study by describing the problem, overall aim, research questions and objectives and my research motivations. The study design is presented with an explanation of theories that guided the development of the theoretical framework and thesis.

1.3 Problem statement

The study began as a problem and a question. The problem being ‘inequalities in the health system’ (Ataguba *et al.*, 2011:1), escalating numbers of chronic disease patients and poor maternal and perinatal mortality trends in rural South Africa. Maternal mortality is high, at 310 deaths per 100,000 live births (WHO, 2013:5). In the adult population 42 per cent are diagnosed with hypertension (Mayosi *et al.*, 2012). It is estimated that 80 per cent of the population has latent tuberculosis (TB) and in 2011 500,000 cases of active TB (SANTA, 2016). Of those, 65 per cent have the double burden of Human Immunodeficiency Virus infection and Acquired Immunodeficiency Syndrome (HIV/AIDS) (WHO, 2014). The country’s adult (15-49 years) HIV prevalence is 19.3 per cent (UNAIDS, 2016). The government are planning a National Health Insurance (NHI) intended to achieve universal health coverage to overcome the inequalities of the health system. In 1995, the government decentralized the provision of health services with the aim of providing all citizens with access to a comprehensive package of primary

healthcare and district hospital services (Pillay, 2004). In the South African primary healthcare model, clinics are nurse-led and are the first point of entry into the health system. These facilities are the cornerstone of care and provide integrated, preventive, promotional, curative and rehabilitation services. Despite national and local efforts to transform the health system, rural communities continue to face barriers in accessing quality healthcare (Goudge *et al.*, 2009).

The question was whether delivery of care could be strengthened by the use of digital communication technology, particularly for patients with chronic disease and pregnant women. This research explores the possibilities of implementing digital systems for primary care considering the social, infrastructural, political, economic and environmental barriers and enablers.

1.4 Overall research aim

The overall aim was to understand the potential for digital communication solutions, particularly mobile devices, to improve public healthcare delivery in rural South Africa.

1.5 Research questions

Research Question 1.

What is the role of mobile phone communication in the monitoring of chronic disease management within public primary healthcare in resource-poor low- and middle-income country settings?

(Answered in Chapter 3)

Research Question 2.

How are digital communication technologies currently being used by patients and health-workers to enhance the delivery of primary healthcare within rural South Africa?

(Answered in Chapter 5)

Research Question 3.

What is the potential for the use of digital communication technologies to enhance primary healthcare delivery in rural South Africa?

(Answered in Chapter 6)

Research Question 4.

What are the government stewardship, organisational, technological and financial enablers and barriers to the use of digital communication technologies for the delivery of primary healthcare in rural South Africa?

(Answered in Chapter 7)

1.6 Study objectives

Objective 1. To undertake a realist review on the role of mobile phone communication in the monitoring of chronic disease management within public primary healthcare in resource-poor low- and middle-income country settings.

Objective 2. To explore patients' and health-workers' current and future use of digital communication technologies within rural South African primary healthcare.

Objective 3. To explore with national policy-makers and eHealth and mHealth experts, the potential for harnessing digital communication to improve primary healthcare in rural South Africa.

1.7 My research motivations

I was intrigued by the possibility that technological solutions, not necessarily designed for healthcare, can solve some of the deeply rooted challenges for healthcare in South Africa. Twenty years on from democracy, with plans for universal health insurance, the National Department of Health (NDOH) are eager to incorporate eHealth and mHealth across the health system supported by external funders and developers. I wanted to understand how this

enthusiasm for digital communication can potentially improve process and health outcomes and whether they can be realised in this context.

Coupled with this intrigue, my motivation and positionality has stemmed from a personal story harboured from experiences growing up as a child in rural South Africa. The story is about my 'Mama Matlala', a 97-year-old Sotho woman, who cared for me during my formative years from birth (Photo 3). I wanted to critically understand why Mama and her daughter Miriam (Photo 2 and 4) still have poor access to healthcare and basic medication in their very rural village. For decades, the nearest clinic has struggled with persistent shortages of blood pressure tablets, needed to stabilise her hypertension. Of particular interest was how Mama's basic mobile phone could enable her to manage her hypertension in the remote part of the Limpopo province, where she lives. To understand this predicament fully, interviewing a cohort of people with chronic disease also living in a rural area, was necessary.

I am a social scientist with a background in health system strengthening. An MSc in Social Policy gave me invaluable analytical and research skills that I wanted to put into practice in the field. I approached this research topic from an evidence-based social intervention perspective rather, than as an information communication technologist. This intrigue, my personal affiliation and a curious mind, compelled me to want to actively contribute to public health research in my native country.



Photo 4. Mama Matlala outside her home in Limpopo province (August, 2014)

1.8 Study design

This thesis contains two literature reviews, a background narrative review of digital communication in South Africa in Chapter 2, followed by a realist systematic review on monitoring of chronic disease using mobile phones in Chapter 3. The empirical research was a critical analysis of qualitative data collected over 12-months. Fieldwork took place at the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) in South Africa, run by the School of Public Health, University of the Witwatersrand (Agincourt, 2016). I aimed to explore the impact of digital communication on access and delivery of healthcare with a range of participant groups:

community members, patients, health-workers, policy-makers and experts. I undertook a secondary analysis of quantitative data from the Agincourt Health and Demographic Surveillance System (HDSS) census data in order to contextualise and aid the interpretation of the qualitative findings.

1.9 Thesis contribution to knowledge

This thesis contributes to knowledge by providing a synthesis of findings, presented in four frameworks. These determine whether the public health system is ready to adopt digital communication solutions for patients and health-workers and where they are likely to work. Findings will contribute to public health policy and practice, and inform future eHealth and mHealth interventions. This thesis does not set out to evaluate whether digital communication improves health outcomes.

1.10 The researcher's epistemological positioning

The realist approach

This study takes 'scientific realism' as its epistemological position (Pawson, 2013), which is rooted in the realist philosophy of science and is a response to positivism. It is borne out of the critical realist perspective of Bhaskar (2013), who recognised the need for both the natural and social sciences to be based on a coherent definition of reality. The realist approach asserts that both the material and the social worlds can have 'real' effects and that it is possible

to work towards a closer understanding of what causes change. Wong (2012) implies that realism assumes that there is a 'real world' and that our knowledge of it is processed through human senses, languages and culture. The task of a realist is to generate theories that explain the social world and identify mechanisms that explain outcomes. The key question is 'what works for whom, in which conditions'. This thesis considers social programmes as social systems. Pawson and Tilley (1997) suggest that social systems comprise of the interplay of individuals and institutions, of agency and structure, and of micro- and macro-processes. Realism paints a complicated picture of the world made up of unobservable underlying mechanisms and structures. Danermark (2002) clarifies that, for realists the ultimate aim of science is explanation of observed phenomena in terms of deeper-level generative mechanisms. This is a two-staged process: 1) conceptualising the causal mechanisms that give rise to events 2) describing how different mechanisms manifest under specific conditions.

The realist philosophy and subsequent theorists (Pawson & Manzano-Santaella, 2012; Wong *et al.*, 2010) have developed distinctive approaches to social research called realist synthesis and evaluation. This research followed the two axioms of realism (Pawson & Tilley, 1997):

<p><i>1. What are the mechanisms for change triggered by a programme and how do these counteract the existing social processes?</i></p>

2. What are the social and cultural conditions necessary for change and how are they distributed within and between programme contexts?

The principles of a realist inquiry were used in the realist synthesis of literature in the systematic review (Chapter 3). The realist approach was then extended in the final analysis of empirical data by using the hypotheses from this review to inform and interpret the qualitative Vutivi findings.

1.11 Theories used to inform the Vutivi study

Theory occupied a central role in this study in the formulation of interview questions and analysis of data. The development of theory ahead of data collection is a core feature of case study design (Lincoln & Guba, 1985).

A number of theories form the theoretical basis for this research. Ragin and Becker (1992) suggest that theories can be modified, reviewed and added to during the research process. The thesis considers health and healthcare delivery from a health systems perspective using constructs of normalisation and capability to contribute to developing the theoretical framework. This section describes the theory, where and how it will be used in this thesis and the links between them.

Health policy and system research theory

A wider health system perspective may offer an opportunity to embed digital communications in the emerging debate around complex adaptive systems and their applications in health. Johnston and Finegood (2015) suggest that systems thinking is about causes and solutions of a complex problem such as, lack of access to healthcare. Koon *et al.* (2013:1) argue that by embedding health policy and systems research into the ‘decision-making’ process, this can strengthen the validity of technical decisions for LMIC health systems. This may apply to the decision-making process in the field of eHealth and mHealth. If healthcare delivery models are based on health policy and systems research these can account for the complexity of health systems by integrating issues such as, access to healthcare to optimise health outcomes. A model by Oni *et al.* (2014:3) is updated in relation to mHealth in Chapter 7. It proposes a re-thinking of healthcare delivery and policy and planning models in order to provide an adequate primary care response to South Africa’s on-going health transition. The model suggests that the health system perspective acts as the umbrella at the macro-level, linking the patient and provider perspectives. In addition, Leon’s *et al.* (2012:5) ‘Health Systems Framework’ designed for mHealth interventions, is used and adapted in this thesis and described in more detail at the end of this section.

Access to healthcare theory

mHealth can be described as the method of moving data from one place to another to improve the channel of communication to provide healthcare access. Access is central to the performance of healthcare systems and remains a complex notion. Access can be defined as ‘the opportunity to reach and obtain appropriate healthcare services in situations of perceived need for care’ (Levesque *et al.*, 2013:4). Levesque’s *et al.* (2013) framework of access to healthcare includes five abilities of populations: 1.) Ability to perceive, 2.) Ability to seek, 3.) Ability to reach, 4.) Ability to pay and 5.) Ability to engage. A WHO document called ‘Right to Health’ (WHO, 2007:4) has been used by academics researching access to healthcare (McIntyre *et al.*, 2009; Goudge *et al.*, 2009) as it includes the terms availability, accessibility, acceptability and quality. The WHO (2006) ‘quality dimensions’ describe the building blocks for identifying tools and strategies for health outcome improvement (Table 1).

Table 1. WHO (2006:9) quality healthcare outcome dimensions

Quality Dimension and Definition
<i>Effective</i> , delivering healthcare that is adherence to an evidence base and results in improved health outcomes for individuals and communities, based on need
<i>Efficient</i> , delivering healthcare in a manner which maximises resource use and avoids waste
<i>Accessible</i> , delivering healthcare that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need

<i>Acceptable/patient-centred</i> , delivering healthcare which takes into account the preferences and aspirations of individual service users as the cultures of their communities
<i>Equitable</i> , delivering healthcare which does not vary in quality because of personal characteristics such as, gender, race, ethnicity, geographical location, or socioeconomic status
<i>Safe</i> , delivering healthcare which minimizes risks and harm to service users.

These dimensions are at the level of policy-makers, service providers and consumers across the whole health system (Peiris *et al.*, 2014). For example, the quality dimension of ‘accessible’ is defined as the timely delivery of care, where skills are appropriate to medical need. All six dimensions can be applied to digital communication technologies. Levesque *et al.* (2013) extend the dimensions of accessibility to include approachability, availability, affordability and appropriateness. These are explored in this thesis.

The Capability Approach theory

This thesis draws on Amartya Sen’s Capability Approach, with particular attention to social exclusion as capability deprivation. In his book, ‘Development as Freedom’, Sen (1999:14) argues that human development is the process of expanding the freedoms that people value and have reason to value. His theory questions the total average well-being and opportunities available to each person (Sen, 1990; Nussbaum, 2011). The approach offers a way of thinking about development not as economic growth but as individual freedom (Kleine, 2010). If capabilities of people are the ultimate

concern (their freedom to lead a life they value), then social inclusion and the ability to participate in the ICT driven ‘e-society’ is important. The idea that ICT is intrinsically desirable and beneficial to society is prevalent and is likely to continue (Zheng & Walsham, 2008).

Warschauer (2003:44) proposes that ‘access for ICT must not rest on providing devices or conduits alone’. The promotion of social inclusion must involve a range of factors such as, physical, digital, human and social resources. The perspective of social exclusion in the e-society is multi-dimensional and varies across societies, cultures and communities. Social exclusion in the e-society is often relational and results from types of capability failure rather than the deprivation of technological usage (Zheng & Walsham, 2008; Braa & Hedberg, 2002). The impact of technology needs to be understood within a rural context (Kleine, 2010) and this can become a focus of public policy along with how normalisation develops.

Normalisation theory

‘Normalisation Process Theory’ (May *et al.*, 2007) sets out to explain the social processes through which new or modified practices of thinking, enacting and organising of work are operationalized in healthcare settings. Normalisation is concerned with implementation, embedding and integration of processes into practice:

Implementation: The social organisation of bringing a practice into action.

Embedding: The process by which a practice becomes or does not become routinely incorporated in everyday work of individuals and groups.

Integration: The process by which a practice is reproduced and sustained among the social matrices of an organisation.

May *et al.* (2007) recognise that establishing new ways of delivering and organising healthcare can be problematic. The theory synthesises what people have to do in order to make a complex intervention workable and integrated into ‘normal’ practice. This thesis will explore the likely policy barriers to the normalisation of innovative digital solutions in healthcare using May’s (2006) framework.

The Vutivi study provides insights into the issues relevant for the normalisation of innovation in health-related technology and services in resource-poor settings. South Africa is becoming rapidly ‘digitalised’, even in deprived areas through mobile phone technology. This research explores how and why digital innovations are not currently normalised and how this might be changed through policy initiatives.

Health Systems Framework used by the South African National Department of Health

The NDOH's (2015a) 'Health Systems Framework' was published in their mHealth Strategy. It is used as a theory in this thesis related to 'health policy and systems research theory'. It was originally developed by Leon *et al.* (2012) with the intention to guide decision-making by policy-makers and managers on mHealth implementation in South Africa. The Health Systems Framework is made up of four dimensions; Government Stewardship, Organisational, Technological and Financial systems (Figure 1).

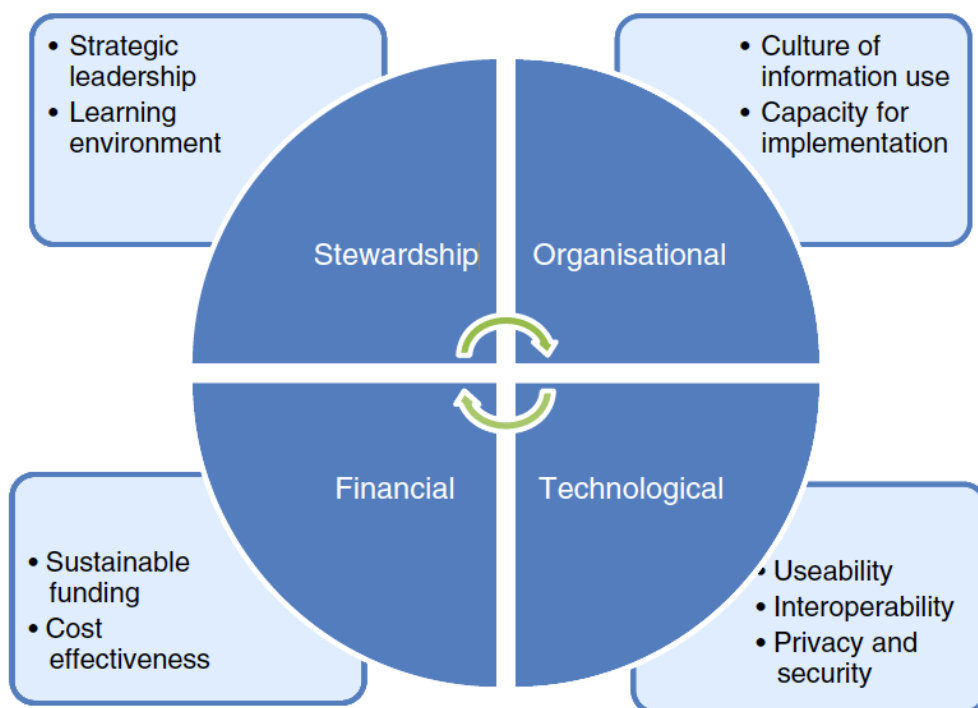


Figure 1. 'Health Systems Framework' diagram for decision-making about mHealth for community-based services (Leon *et al.*, 2012:5)

Leon's *et al.* (2012:5) framework links four interconnected health system dimensions to health system capacity requirements (further described by Leon in Table 2). She argues these should be addressed when making decisions about mHealth implementation.

Table 2. Explanation of the Health Systems Framework: Health systems dimensions required for scaling up mHealth for community-based health services (Leon & Schneider, 2012:6)

Health system dimension	Health system capacity requirements
Government stewardship: Is there a policy environment supportive of mHealth?	<ul style="list-style-type: none"> • Strategic leadership: Strategic leadership is present through policy guidelines that promote alignment with strategic health goals, funding sources, common ICT standards and partnerships for collaboration nationally and internationally. • Learning environment: Government stewardship includes creating a learning environment, where projects are evaluated systematically and where collaboration and sharing of knowledge can contribute to a central repository of evidence on mHealth, which in turn can influence policy and practice.
Organisational: Is there a culture of and capacity for using information technology for management?	<ul style="list-style-type: none"> • Capacity for implementation: The health system has the capacity, managerially and technologically, to successfully implement mHealth interventions. This includes assessment of eReadiness, a functional ICT environment and effective mechanisms for implementation, support and monitoring and evaluation. • Culture of information use: There is an organizational culture and tradition of using health information for management - to ensure that the increased access to electronic information is used for quality improvements in health services.
Technological: How useable, integrated and sustainable is the chosen technology?	<ul style="list-style-type: none"> • Use-ability: The technology has ease of use, flexibility and durability and end users experience the new technology as benefiting their work. • Interoperability: Interoperability of information systems ensures there is smooth communication across technological and information platforms as well as smooth integration with existing work practices. Common standards (required for interoperable systems) are developed through consensus amongst the multiple stakeholders including health ministries, digital providers, health management, clinical staff, patients, and funders. The relative merits of open source versus proprietary software are addressed as this has implications not only for interoperability, but also for financial sustainability. • Privacy and security: Privacy and security of data is ensured. Additional regulations for protecting electronic data may be required to secure privacy of data.
Financial: Is adequate financial provision being made for the medium to long term use of mHealth?	<ul style="list-style-type: none"> • Sustainable funding: Securing sustainable funding for large-scale implementation is a major requirement and requires clear business and funding plans. Plans should be realistic, especially as ICT projects may cost more and take longer than initially planned. • Cost-effectiveness: The cost-effectiveness of mHealth strategies is evaluated. mHealth interventions are weighed up against other priority and evidence-based interventions (in terms of the costs, resources and capacity requirements), and opportunity costs are routinely considered. Unintended consequences of introducing new technology within a weak health system are monitored to minimize negative effects.

This framework is linked to the other theories introduced because mHealth implementation needs to consider access to healthcare, capability to use the technology and normalisation to incorporate the technology into routine.

Leon's framework will be adapted in Chapter 7 using the findings from the Vutivi study to appraise, update and reiterate the opportunities and challenges to effective implementation of mHealth at scale in health systems.

1.12 The Vutivi study's theoretical framework

Miles (1994) suggest that a visual theoretical conceptual framework can be useful to guide the researcher. A visual theoretical framework for the Vutivi study has been drawn to illustrate the epistemological stance, perspectives and high-level theory used in this thesis to guide the empirical research (Figure 2).

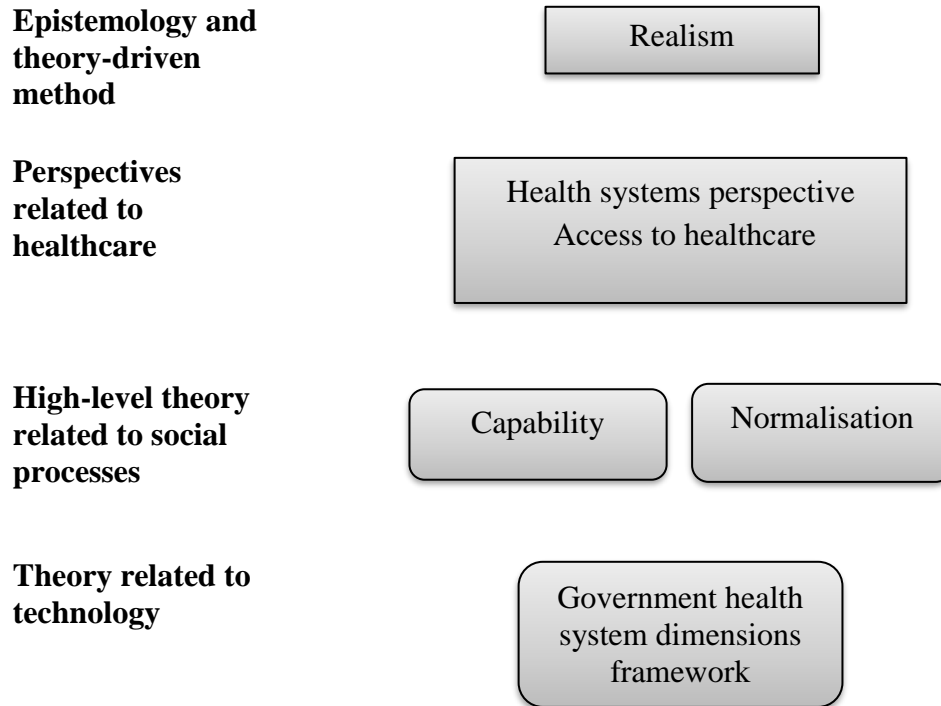


Figure 2. Vutivi study theoretical framework to guide the analysis

This framework summarises the theory that informed the analysis. The realist review in Chapter 3 and empirical results in Chapter 6 and 7 uses realism to identify how causal mechanisms are shaped and constrained by social context. Realism as a theory-driven method, guide the development of the programme theory, Context-Mechanisms-Outcome configurations and consolidated theories. Theories related to healthcare including health systems perspective, access to healthcare, capability and normalisation are used to guide the interpretation of results and discussion in Chapter 8. Finally, the

Health Systems Framework is used as theory and revised in light of the Vutivi findings and used to develop the healthcare delivery model in Chapter 7.

1.13 Overview of the Vutivi study thesis

This thesis has eight chapters. Chapter 1 has provided an introduction to the thesis and outlined the research questions, design and theoretical framework. Chapter 2 is a background narrative review to provide literature on the South African health system and eHealth and mHealth in the country. Chapter 3 is a systematic realist review on mHealth monitoring interventions for patients with chronic disease to answer Research Question 1. Chapter 4 describes the study design, methodology and methods. Results Chapters 5, 6 and 7 present the findings for Research Questions 2-4 on current and future use of digital communication technologies in primary care and enablers and barriers to their uptake. Chapter 8 synthesises the results for each research question, links the findings to current literature and theory, and considers study limitations and strengths and future research and policy implications for public health care.

Chapter 2



Photo 5. Mama Miriam outside of her family home (November, 2013)

Chapter 2: Background to the South African health system, eHealth and mHealth and national policies: a narrative review

2.1 Overview of the narrative review in Chapter 2

Chapter 1 presented an outline of the Vutivi study. This chapter provides a narrative literature review to give an overview of the field of study to situate the research results. First I provide an introduction to South Africa, and its health system, chronic disease burden and maternal mortality trends. I then give a general outline to eHealth and mHealth, followed by an introduction to the digital communication landscape within South Africa. I will refer back to these topics in the course of the results and final discussion.

2.2 General introduction to South Africa's health system

South African politics and economy

South Africa is formally classified by the United Nations (UN) as a middle-income country and an advanced emerging economy with a medium Human Development Index (UN, 2013). The historical and widespread poverty, and patterns of racial and geographical inequality, lower South Africa's human development indices (Leon *et al.*, 2015b). South Africa made the transition from an apartheid state to a constitutional democratic state in 1994 (Schneider & Stein, 2001). The country has experienced economic growth but inequality and poverty have also increased (Papaioannou *et al.*, 2015). Severe inequities persist between socio-economic groups and geographic regions (McIntyre,

2012). The extent of poverty has changed little since democracy, when the African National Congress (ANC) party came to power. South Africa's 'well developed system of social security' (Booyesen, 2004:45) has been deployed as 'an anti-poverty tool' (Marais, 2011:3). Social protection in the form of grants includes state pension, child support, disability and foster care grants (Woolard & Leibbrandt, 2013). Cleary *et al.* (2013:38) suggest that social grants can alleviate 'out-of-pocket payments for district healthcare'. In 2014 unemployment figures were at 24.3 per cent of the total population (StatsSA, 2015). South Africa has a widespread shortage of skills partly as 'a legacy of apartheid and the continued dysfunctionality of the South African education system' (Edigheji *et al.*, 2010:25).

South Africa's expenditure on healthcare

South Africa is a democracy still in its infancy, with a history of oppressive colonisation and apartheid. This has affected the social determinates of health (Coovadia *et al.*, 2009). Health outcomes are not in line with expenditure. South Africa spends 8.7 per cent of Gross Domestic Product on health, more than any other African country (Badiie, 2008).

South Africa's current public sector healthcare provision

The majority of the population in South Africa (81.3 per cent) are entirely dependent on public sector healthcare (Lehohla, 2011). Primary health

services are free at the point-of-care. The country is ‘undergoing a major health system restructure in an attempt to improve health outcomes and reduce inequities in access’ (Versteeg *et al.*, 2013:119). The on-going healthcare reforms provide an opportunity to incorporate issues of complexity associated with chronic disease into the strategic objectives of the government’s primary care re-engineering. This revised system operates in clinics, district hospitals and community health centres (Coovadia *et al.*, 2009). The provision of these services is hampered by the shortfall of human resources, poor management and supervision of staff, which can affect health-worker performance (Scott *et al.*, 2012; Wringe *et al.*, 2010; Rowe *et al.*, 2005) and morale (Kleinert & Horton, 2009). There are often ‘stock-outs’ of essential drugs, budget constraints, an absent recall system for non-attenders and inadequate patient records (Levitt, 2008).

Rural healthcare provision

A key factor influencing rural health is income and poverty (Vergunst *et al.*, 2015). Many of the rural population receive inadequate health services. There are racial, socio-economic and rural-urban differentials in health outcomes (Gilson *et al.*, 2007). van der Hoeven *et al.* (2012) found that rural communities have a lower available weekly budget, not only for healthcare but also for transport to the health facility. Rural facilities are usually further

away from households therefore transportation costs and distance are key access barriers (Harris *et al.*, 2011).

The South African health system's challenges

The South African health system has a backdrop of poor governance, management and accountability and resource-poor primary healthcare with 'inadequate access and quality care' (Leon & Schneider, 2012:9). The health system has struggled to overcome the legacy of apartheid and the consequent inequitable distribution of resources based on factors such as, race, class and geographic location (McIntyre *et al.*, 2002). The challenges in rural contexts where historical neglect and high levels of material deprivation exist are also hindered by lack of infrastructure and equipment and human resource challenges (Schneider *et al.*, 2006).

Disease burden in South Africa

The general disease burden for the South African population includes 30 per cent of 20-24 year olds infected with HIV/AIDS causing 43 per cent of adult deaths (Mayosi *et al.*, 2009:8).

South Africa's antiretroviral treatment (ART) programme has generated substantial knowledge relevant to other chronic diseases (Chigwedere *et al.*, 2008). This includes adherence support, tracing defaulters and enabling

patient participation through treatment literacy and patient support groups (Schneider *et al.*, 2006). Adherence to medication is often sub-optimal and insufficient attention is paid to the burden of co-morbidities (Thorogood *et al.*, 2014) known as the ‘collision of disease epidemics’ (Coovadia *et al.*, 2009:817; Levitt *et al.*, 2011).

Sub-Saharan Africa is in the midst of a rapidly evolving economic and epidemiological transition (Thorogood *et al.*, 2007; Tollman *et al.*, 2008). This is especially due to the rising burden of non-communicable diseases (NCD) (Mensah & Mayosi, 2013) and comorbidities (Ebrahim *et al.*, 2013). The mode of healthcare delivery has had to change to best cope with situation. For example, growing numbers of people living with HIV/AIDS and/or TB also struggle to cope with one or more NCDs (Geneau & Hallen, 2012). Treating patients with co-morbidities is challenging for low-resource health systems because of the complexity of patient care required (Bates *et al.*, 2015). The quality of clinical management for people with long-term disease is dependent on the variation in how well primary care functions. To improve the continuum of care, the NDOH is shifting from acute episodic care to a chronic care model.

The South African ‘Integrated Chronic Disease Management’ (ICDM) model incorporates community, patient, healthcare and policy perspectives. It

presents a unique opportunity ‘to tailor health services for the prevention and control of chronic diseases’ (Ameh *et al.*, 2014:2). The model is based on a public health approach to empower individuals to take responsibility for their own health (Asmall & Mahomed, 2014:148). Components of the model are to include ‘mobile technology’ as a health system building block (Asmall & Mahomed, 2014:11) (Figure 3).

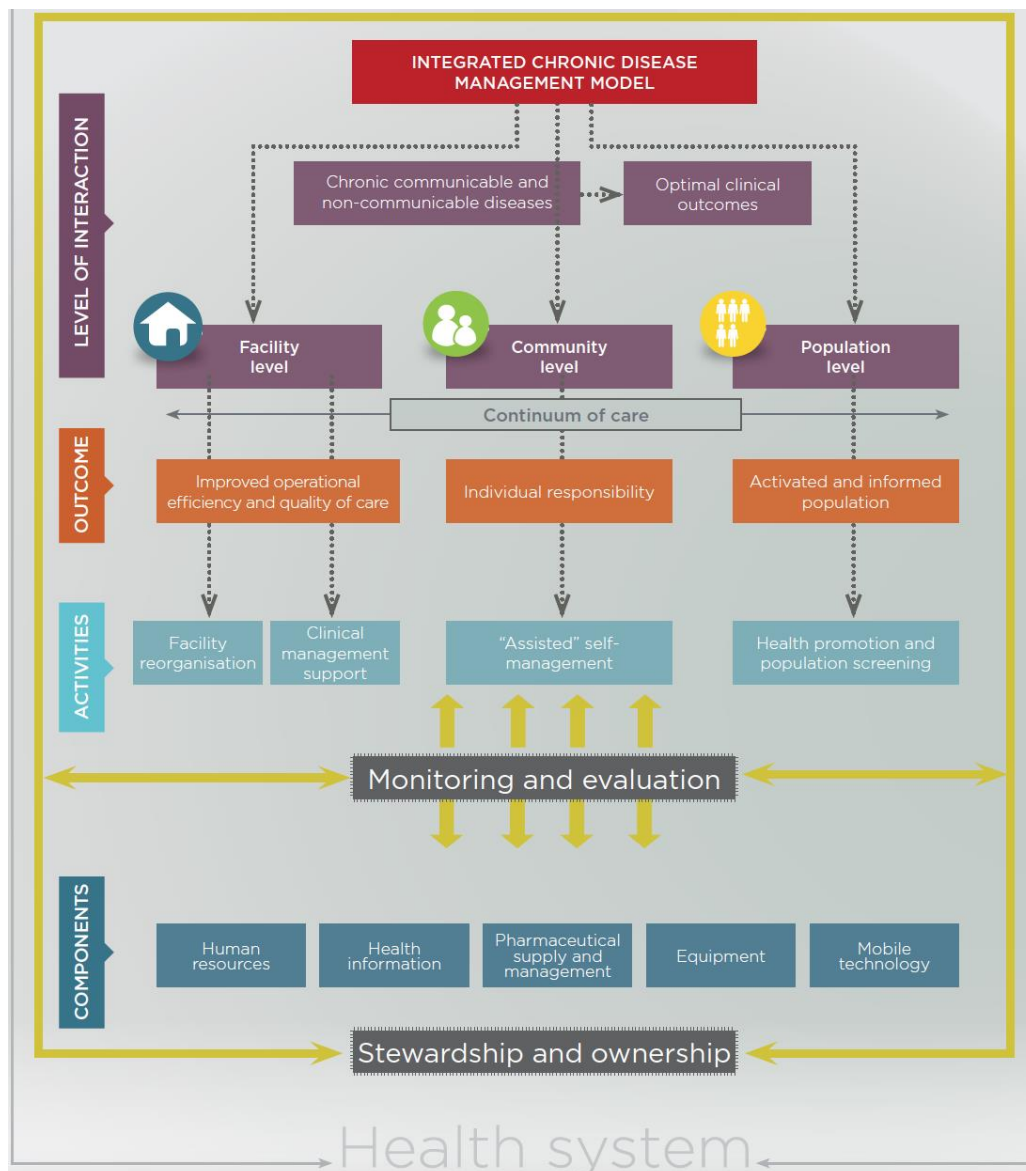


Figure 3. South African ICDM model including the component of ‘mobile technology’ in the bottom right hand blue box (Asmall & Mahomed, 2014:11)

Maternal health in South Africa

The aim of Millennium Development Goal 5 was to reduce by three quarters, the maternal mortality ratio and achieve universal access to reproductive healthcare. South Africa fell short of achieving this goal by the end of 2015.

The national maternal mortality average was 133 deaths per 100,000 births in 2014 (van Shaik, 2015:69). In the area where the fieldwork for this thesis was undertaken, the mortality rate due to obstetrical causes in 2012 was 252 deaths per 100,000 births (Garenne *et al.*, 2013). This is higher than the provincial average for Mpumalanga (MP), at 149.1 deaths per 100,000 births in 2013, and 115.4 per 100,000 in 2014 (Figure 4).

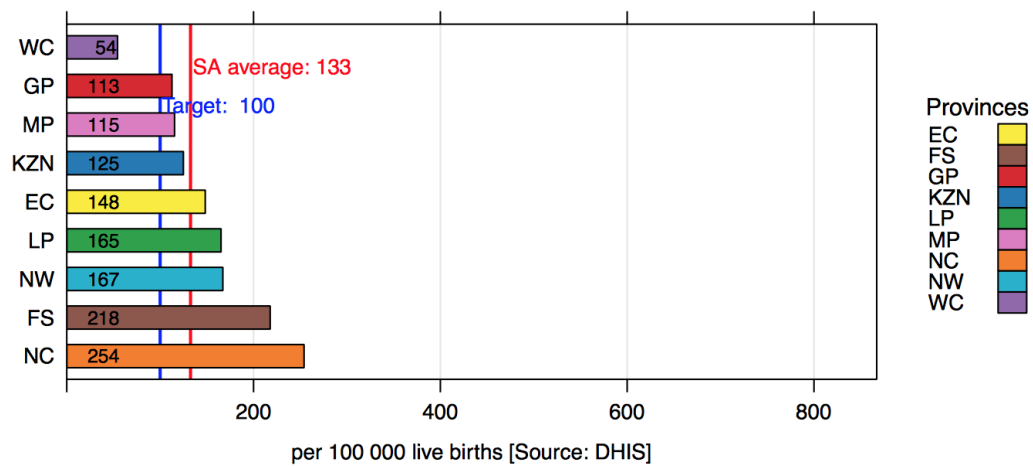


Figure 4. Maternal mortality data in facility ratio by province 2014/15 from the District Health Information System (van Shaik, 2015:69)

In the most recent national publication of health statistics, called the ‘District Health Barometer’ 2014/15, the high numbers of maternal deaths were attributed to late referrals, lack of identification of complications, shortage of doctors and ambulances, increased numbers of mothers with HIV/AIDS and ‘use of traditional medicine and alcohol abuse by pregnant women’ (van Shaik, 2015:80). High mortality rates have previously also been associated with poor socio-economic conditions, malnutrition and a lack of antenatal

care often due to a chronic shortage of equipment and service providers (Duminy & October, 2005). More recently, Clouse *et al.* (2013) found that pregnant women with HIV can be at heightened risk of loss to follow-up for their antenatal visits. The government's strategy for improving maternal and perinatal healthcare has been to focus on capacity building of health-workers and advancing the competence and skills of mid-wife nurses (Gilstad, 2012).

A major reason for untreated pregnancy and childbirth complications that lead to large numbers of maternal deaths, particularly in rural communities, is the limited access to basic maternity information (Destigter, 2012). Other barriers to accessing antenatal care include the lack of or cost of transport to the health facility (Chopra *et al.*, 2009). Traditionally there has been a trend of 'women seeking antenatal care late in pregnancy in rural South Africa' (Myer & Harrison, 2003:268). The reasons included the perception that pregnancy was not a health threat and that one antenatal care visit was adequate.

2.3 eHealth and mHealth in LMICs

There are approximately 6.8 billion mobile phone subscriptions worldwide with 89 per cent penetration in developing countries (ITU, 2013). There has been a particularly rapid spread of mobile penetration in Sub-Saharan Africa and mobile phone use is almost ubiquitous in South Africa (GSMA, 2013).

The availability and uptake of eHealth and mHealth in high-income countries has been cited and evaluated in the literature (Vodopivec-Jamsek *et al.*, 2012; Black *et al.*, 2011). This has ignited interest into the potential implementation of digital solutions to enhance healthcare in LMICs (Blaya *et al.*, 2010; Lewis *et al.*, 2012). The rapid proliferation of mHealth projects in LMICs has generated considerable enthusiasm among governments, donors, and implementers of public health programmes. Though many mHealth pilot projects have not materialised into impact-generating programmes (Donner & Mechael, 2012).

There is modest evidence for effective digital health solutions for improving behaviour change, data collection, registries, training and education, and electronic decision-support (Hall *et al.*, 2014). Källander *et al.* (2013:1) argue that it is very challenging to move mobile phone-based interventions from 'pilot projects to national scalable programmes whilst properly engaging health-workers and communities in the process'. Furthermore, most mHealth interventions in LMICs are based in non-governmental organisations (NGOs) and are not integrated into mainstream public health services (Mechael *et al.*, 2010). Kirigia *et al.* (2005) call for each African government to make necessary investments in ICT infrastructure and rural electrification. This would assist in attracting private investment in ICT and strengthen human

capacities for digital technology utilisation at all levels of the health system, in pursuit of public health objectives.

It is argued that the potential for digital communication to significantly change and irrevocably improve the delivery of healthcare services and patient care in rural communities should be explored (Ruxwana, 2007; UN, 2012). However, there is still a deficit of evidence for how mHealth may be impacting on quality and efficiency in terms of improving service delivery processes, strengthening health systems and improving health outcomes (Mechael *et al.*, 2010). There is a need for robust evaluation of quality, safety, cost implications and acceptability before large-scale rollout of mobile-based systems (Car *et al.*, 2008).

Donner and Mechael (2012:142) propose that the rollout of mobile phone technology for health has to consider five aspects presented in Box 2.

1. Low literacy levels in rural Africa can mean that the end-user of a SMS may not be able to read the message.
2. Mobile phone operators seek a win-win market situation so pilot projects are often subsidised by a commercial partner so the end-user do not pay for the services, however there are issues of feasibility in the long-term.
3. Low rural mobile penetration remains a factor.
4. Frequently mobile phones are shared in one household unit with ownership bound to the male (suggesting cultural/traditional power relations/social norms).
5. The design of the SMS is limited to 160 characters and as such content must also be developed with local, cultural, religious and demographic differences in mind.

Box 2. Five factors to be considered for rollout of mHealth by Donner and Mechael (2012:142)

These factors can be further developed to include the adaption of current technologies to be context specific. Technology developers are beginning to focus more on adapting rather than designing new technologies. ‘Frugal technologies’ (Howitt *et al.*, 2012:1) are specifically designed to meet the needs of LMICs. Howitt *et al.* (2012:3) believe that technology by its self ‘is rarely sufficient to improve health outcomes’ otherwise there may be unintended negative consequences from introducing new technologies into a system. Often when ‘technological fixes’ have been imposed on communities, abandoned equipment, incompatible computer programmes and ineffective policies have resulted (Fong & Harris, 2015:438). The WHO (2011) suggest that eHealth can use valuable resources and potentially cause harm if implementation is not guided by evidence. Fuchs and Horak (2008:99) warn of the ‘Digital Divide and Africa’ and the potential for mobile phones to contribute to inequalities to access and ‘usage and usage benefit’.

The Groupe Speciale Mobile Association (GSMA, 2014:12) emphasised the barriers for mHealth (Figure 5) such as, user-retention and changing phone numbers, which they found are common features in South Africa.

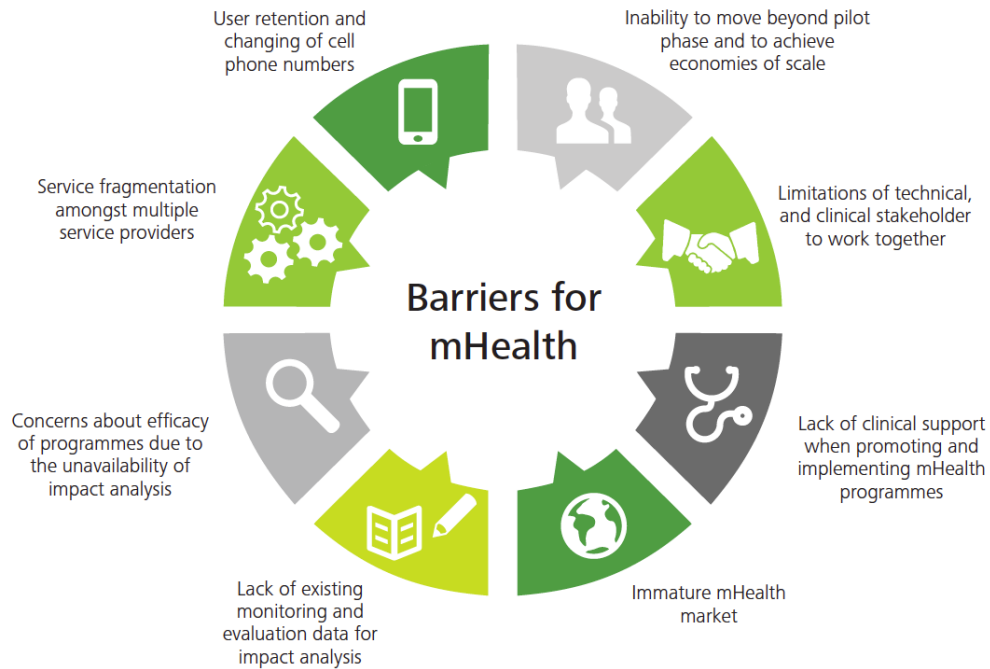


Figure 5. Key barriers to consider when implementing mHealth solutions by the GSMA (2014:12)

Labrique's *et al.* (2013:168) '12 Common mHealth and ICT Application Framework' (Figure 6) suggest the aspects of healthcare where there is potential for mHealth to have impact on healthcare delivery. This taxonomy guides what possible mHealth solutions can be identified as viable in a rural health system context in the results chapters.



Figure 6. ‘12 Common mHealth and ICT Application Framework’ by (Labrique et al., 2013:168)

This thesis does not specifically focus on any one mHealth solution listed in the framework. The aim of the explorative nature of this research is to give a generalised overview of what is currently available or has the potential to work in this context.

2.4 eHealth and mHealth in South Africa

Despite the many health system challenges, the South African government is committed to investing in a future health system that encompasses the use of digital solutions. A comprehensive primary healthcare system that uses digital communication technology is a priority of the government in its plans for the NHI.

South Africa has a positive political environment for eHealth and mHealth implementation because as Leon and Schneider (2012) suggest, there is a high prevalence of mobile phones, a well-developed ICT industry and government support. South Africa currently has the largest telecommunications market in Africa (GSMA, 2013). The country's low uncapped mobile prepaid broadband pricing is among the highest compared to ten other African countries (Gillwald *et al.*, 2012). The GSMA (2013) suggests that the three major South African network providers cover 90 per cent of the country although the rollout of 3G, remains largely in urban areas.

In South Africa 84.2 per cent of households own a mobile phone (Gillwald *et al.*, 2012:49). The South African census only measures household use of mobile phones and not individual use. There is little difference between phone ownership in urban and rural areas and between people with the greatest wealth and those living on the basic poverty line (R432 per month) (StatsSA, 2011; NPC, 2011).

South Africa's prepaid mobile voice services are costly by continental and global standards (Gillwald *et al.*, 2012). Broadband penetration in South Africa is sub-optimal in comparison to other middle-income countries. Gillwald *et al.* (2012) argue that affordability is critical in accelerating diffusion of the Internet. Many data-users opt for a 3G USB dongle modem to access the Internet, as ADSL fixed-line connections are not always

possible, especially in rural areas where infrastructure is limited (Chetty *et al.*, 2013:1). The most predominant means of Internet access is via a mobile phone (NPC, 2011). The use of the Internet via mobile devices is expected to increase as access to low-cost Internet-enabled devices rises. However in the 2011 census survey 61.6 per cent of rural people said they do not know what the Internet is (Gillwald *et al.*, 2012:66). A total of 60.8 per cent of rural respondents were signed-up to a social network such as, Facebook, Mxit (a popular South African social media network) or Twitter (Gillwald *et al.*, 2012:61). The use of social networks and the Internet as a source of health information is very unknown amongst the general public who access the government health system. Hampshire *et al.* (2015) has found that South African adolescents were already using mHealth informally via their phones such as, using social networks and consulting the Internet to obtain health advice about specific symptoms and medicines.

Leon *et al.* (2015b) argue that the high prevalence of mobile phone ownership in South Africa allows for phones to be used to improve delivery of healthcare. Bobrow *et al.* (2014:2) suggest that ‘mobile phone-based interventions could address individual-level factors in health by facilitating timely patient access to relevant health information and support’. This can make patient-provider communication easier and provide context-specific support (Heron & Smyth, 2011).

In the public health sector in 2013, only 13 per cent of rural health facilities were connected to broadband (DOC, 2013). This figure is rapidly changing, as the NHI pilot districts are already connecting all clinics to broadband. In the Limpopo district of Vhembe, 90 out of its 123 primary health clinics are already connected to Broadband as part of this pilot (Wolmarans, 2015).

2.5 South African policy relating to digital communication and its use for health

During the Vutivi study there was policy debate about the implementation of eHealth and mHealth in South Africa.

The following national policies are relevant to eHealth and mHealth implementation.

- The National eHealth Strategy (2012–2017)
- The National mHealth Strategy (2015-2019)
- National Health Normative Standards Framework for Interoperability in eHealth in South Africa (2014)
- The National Integrated ICT Policy Green Paper (2014)
- The South African Connect Broadband Strategy (2013)
- National Health Insurance Green Paper (2011) & White Paper (2015)
- District Health Management Information System Policy
- The National Health Act (2003)
- National Development Plan 2030 (2012)

The National eHealth Strategy 2012–2017

The aim of the National eHealth Strategy is to leverage eHealth to support the broader transformation of the health sector. In July 2015 the NDOH published a notice in the Government Gazette on the establishment of the ‘Ministerial Advisory Committee on eHealth’. The Minister of Health suggests that the government will ‘closely monitor the implementation, to ensure that previous errors do not revisit us’ (NDOH, 2012b:5). One of the major principles of the eHealth Strategy is to constantly evaluate any eHealth initiative. This will measure improvements in health outcomes to build an evidence-base that demonstrates the net benefits of eHealth to ‘guide planning and decision-making’ (NDOH, 2012b:8). There are widely differing levels of eHealth maturity across and within the nine South African provinces. Several previous initiatives have not reached completion due to issues of poor planning, management or lack of funding (NDOH, 2012b:10). For example, telemedicine projects have failed to survive past the pilot phase, resulting in the NDOH placing a moratorium on their implementation (Leon *et al.*, 2012). While the development of the eHealth Strategy was an important milestone, its actual impact will depend on effective implementation monitoring and evaluation (Masilela, 2014).

The National mHealth Strategy (2015-2019)

A sub-component of the eHealth Strategy is the mHealth Strategy published in 2015. The government's mission is to apply mHealth as an integral part of delivery of healthcare services in order to 'empower patients with information, improving access to health services and real-time data management to assist in addressing the current inefficiencies in service delivery' (NDOH, 2015a:6). South Africa lacks an overarching legal framework for eHealth and mHealth necessary to govern and regulate when and how technology is utilised. Nevertheless, South Africa has legislation to protect patients' health records (The National Health Act 61 of 2003) that includes the electronic transmission of personal medical information networks (Broomhead, 2015). The Protection of Personal Information Act (POPI) (NDOH, 2013) supports this.

mHealth Strategy Roadmap

In order to deliver the mHealth implementation plan, the government has set out ten interdependent priority areas and foreseeable challenges of mHealth projects.

mHealth Strategy priority areas:

1. Strategy and Leadership
2. Stakeholder Engagement
3. Standards and Interoperability
4. Governances and Regulation
5. Investment, Affordability and Sustainability
6. Benefits Realisation

7. Capacity and Workforce
8. eHealth and mHealth Foundations
9. Applications and Tools to support Healthcare Delivery
10. Monitoring and Evaluation of the mHealth Strategy

Challenges encountered in mHealth projects:

- Lack of alignment and integration of the interventions into health plans, strategies and systems
- Absence of government leadership and coordination
- Poor documentation and learning from best practices
- Lack of use of open-source options
- Absence of practical approaches to privacy and security
- Lack of interoperability
- Absence of a single framework within which to evaluate the role of mHealth and eHealth tools in strengthening the health system

Box 3. mHealth Strategy Roadmap with priority areas and challenges encountered (NDOH, 2015a:11)

Government mHealth initiative: MomConnect

This section briefly describes the first major government-initiated scaled-up mHealth programme to date: MomConnect (discussed in-depth in Chapter 7). It aims to improve pregnancy registration and client empowerment through increased knowledge and access to services and outcomes during the antenatal and postnatal period for mother and child (Massyn, 2015). Mothers receive stage-based messaging during pregnancy and up to one-year after the child's birth. The goal is for all 1.2 million women who become pregnant annually to be registered (van Shaik, 2015). 'MomConnect illustrates the strong desire and political pressure to take advantage of ICT and to benefit from improved health messaging' (Waldman & Stevens, 2015:34). South Africa's Health Minister praised its initial success 'in only eight months we

have been able to register 383,354 pregnant women. It is regarded as the largest number in the world' (Motsoaledi, 2015:1).

National Health Normative Standards Framework for Interoperability (2014)

A response to the lack of interoperability listed in the mHealth Roadmap in Box 3, is the 'National Health Normative Standards Framework for Interoperability'. Those standards include issues such as, data security, access control, safe guards and confidentiality. 'An interoperable mHealth system needs to ensure that various routine and other information systems are able to connect, communicate and share information' (Leon *et al.*, 2012:10). The NDOH (2014a) advocated that implementing an open architecture and interoperability framework collaboratively between the public and private health sectors will have benefits. These include ensuring health messaging is consistent and harmonized at the national level, while being adapted and extended for local environments. Another aim of the framework is to align the different service providers to current NDOH objectives such as, primary healthcare strengthening and maternal and child health initiatives.

The National Integrated ICT Policy Green Paper (2014)

The National Integrated ICT Policy Green Paper published in 2014 includes regulation on the distribution of audio-visual, cyber-security/data retention, and Internet infrastructure (Thorton, 2014). Related to this is the Broadband

Strategy. Both are not directly used in this thesis as they relate to ICT beyond the public health sector.

The South African Connect Broadband Strategy (2013)

The Broadband strategy is called ‘South Africa Connect: Creating Opportunities, ensuring Inclusion’ (DOC, 2013). The Minister of Communication said ‘the greatest challenge is how to approach infrastructure development in rural areas where it is clear that the private sector does not show interest to invest in infrastructure capability for Internet connections and high-speed access to data’ (DOC, 2013:21).

One of the reasons the eHealth Strategy has fallen behind schedule is due to poor broadband connectivity. This remains a critical challenge in primary healthcare facilities in rural areas. Telkom and Sentech (state-owned companies) both quoted over five hundred million Rand to provide connectivity to all primary healthcare clinics. Masilela (2014:22) states that exorbitant services charges was ‘a key impediment’ to implementation’. He suggested that the solution is to share costs with other government departments who will also benefit from the required infrastructure.

National Health Insurance (NHI) Green Paper (2011) and White Paper (2015)

South Africa is on the brink of effecting significant changes to its health system financing mechanisms with the recent publication of the NHI white

paper (NDOH, 2015c). The NHI is based on the principles of ‘ensuring the right to health for all, entrenching equity, social solidarity, and efficiency and effectiveness in the health system in order to realise universal health coverage’ (McIntyre, 2012:1). The health system has steadily been undergoing reforms under the umbrella of the NHI since the publication of the Green Paper in 2011 (NDOH, 2011). The purpose of these reforms is to refocus the health system from hospi-centric and curative to a primary healthcare approach. The reforms are underpinned by health promotion, disease prevention and community-centred service delivery. Such reforms aim to radically transform and improve access to healthcare for historically neglected rural communities (Naidoo, 2012). NHI will be phased in over fourteen years to enable universal, equitable and affordable healthcare coverage (Mayosi *et al.*, 2012). This will include training nurses in chronic disease management, equipment and human resources audit, improvement of drug supply, re-organising the patient flow and the establishment of a patient filing system with effective retrieval and storage (NDOH, 2011). The NHI will only be possible, if ‘persistent structural inequity in the distribution of financial, human and material resources such as, medicines, medical equipment and basic infrastructure’ are addressed (RHAP, 2015:2).

Part of the NHI reform is the concept of the ‘Ideal Clinic’ as a strategy to respond to the current deficiencies in the quality of primary healthcare

services. The Ideal Clinic has been integrated into the clinical guidelines of ‘Primary Healthcare 101’ (NDOH, 2015b).

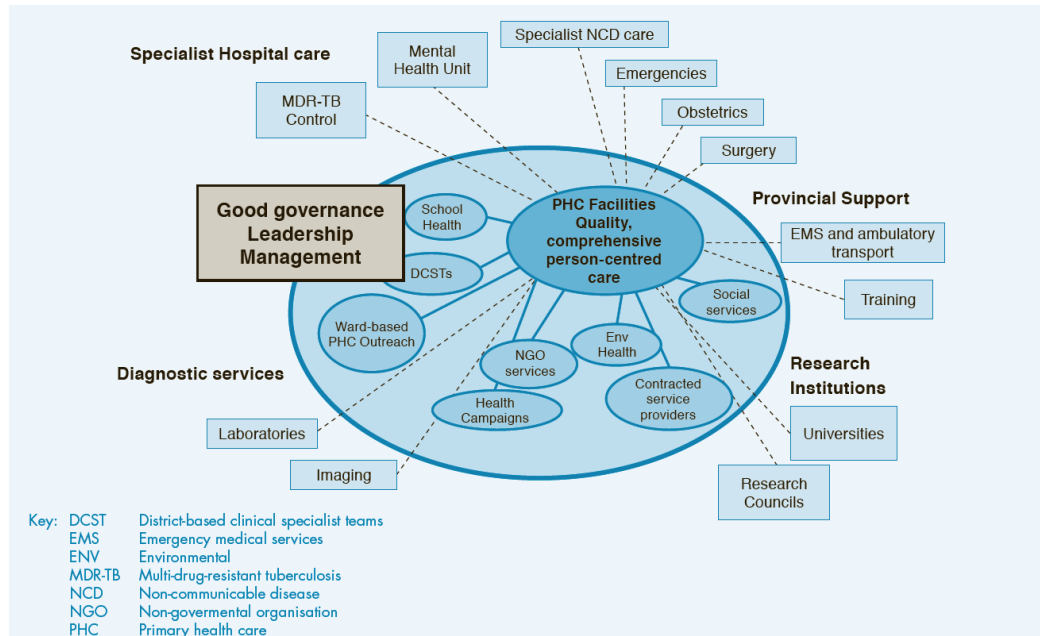


Figure 7. Graphic representation of the Ideal Clinic (Fryatt & Hunter, 2015:25)

An Ideal Clinic aims to ‘provide a comprehensive range of integrated services’ (Fryatt & Hunter, 2015:23), indicated in Figure 7. Part of the government’s aim is to make health facilities paperless and connected to broadband throughout the country, using a patient information system. The Ideal Clinic includes ‘Ward-Based Primary Healthcare Outreach Teams’: six community health-workers, a professional nurse and one health promotion practitioner. These teams are an effective way of responding to ‘South Africa’s crisis of healthcare’ (Kinkel *et al.*, 2013:8).

Another government aim for the successful implementation of the NHI is to improve the quality of data collected for the District Health Information System (DHIS) and make it web-based. This system was designed to facilitate data collection in public healthcare facilities for quality assurance, monitoring and supervision at the national level (Braa & Hedberg, 2002; Seunanden, 2014). The DHIS contains routine data representing ‘1.4 billion patient encounters’ (Masilela, 2014:17).

National Development Plan (NDP) 2030

The National Development Plan (NDOH, 2012a) published in 2012, aims to eliminate poverty and reduce inequality by 2030. It recognises that the public health system cannot meet demand or sustain quality without strengthening primary care services and broadening district based health programmes. The NDP aligns with the United Nations Sustainable Development Goals for 2030 (UN, 2015). All of the relevant policies discussed thus far are embedded within this plan. One of the NDOH aims of the NDP is to develop an efficient health management information system for improved decision-making (Day & Gray, 2015).

Overview of the policies presented

The relationship of these policies is illustrated in Figure 8.

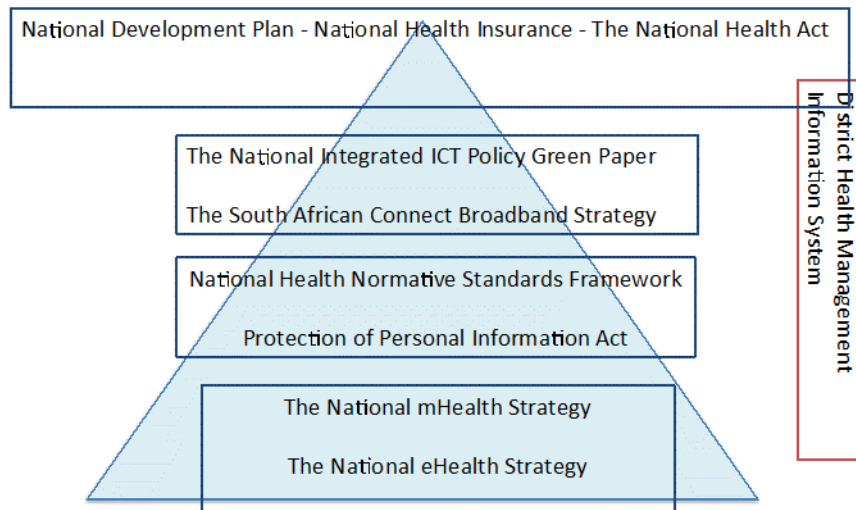


Figure 8. The relationship of South African policies related to eHealth and mHealth used to inform the Vutivi study

The baseline of the triangle in Figure 8, consists of the central eHealth and mHealth Strategies as the foundation or building blocks for the other policies. The Normative Standards, POPI Act, ICT and Broadband policies are interwoven into the core of the eHealth and mHealth documents. The tip of the triangle is the country's national health insurance, development plans and act that build on the implementation of all the other policies, in particular the success of the eHealth and mHealth strategies. This diagram has been created to inform the Vutivi study's findings.

2.6 eHealth and mHealth policy implementation barriers

The challenges facing the adoption of digital solutions in South Africa include historical issues, limited resources, low-literacy levels and professional isolation (Littlejohns *et al.*, 2003). Herselman and Jacobs (2003:64) propose that the ‘development of the local economy’ in rural South Africa is severely compromised by the lack of infrastructure, services and expertise. Masilela (2014) extends these challenges by describing the large number of disparate systems with little or no interoperability and communication, inequity of eHealth services across provinces and expensive broadband connectivity.

Policymakers are not fully familiar with ICT to address health challenges (Asamoah-Odei *et al.*, 2011). Ineffective policy implementation hinders the reform process such as, ‘weak leadership and institutional incapacity limits the development of a comprehensive ICT strategy’ (Waldman & Stevens, 2015:22). However, the government remain positive that the ‘eHealth Strategy for Public Health in South Africa ushers in a new era of optimism about the capabilities of the health information system’ (NDOH, 2012b:5).

2.7 Summary of the narrative review

This chapter has covered the South African health system including a discussion of the chronic disease burden and maternal health. It has

introduced the digital infrastructure and documented policies relating to eHealth and mHealth.

This review was necessary to provide context and background for the Vutivi study and identify areas of limited research. Still not enough is known about the social, organisational and cultural elements of successful implementation and adoption of eHealth and mHealth within the South African healthcare system (Leon *et al.*, 2012). These research gaps will be addressed in answer to the Research Questions 2-4.

In addition, the lack of evidence for the effectiveness of mHealth for chronic disease patient management was evident. The use of digital communication technologies between patients with chronic disease and health-workers was an area of interest in this thesis. eHealth is too broad to review and is more about systems, whereas a focus on mHealth is inclusive of the users of the digital communication technology. To answer Research Question 1, a review to systematically synthesise the current literature follow.

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The next chapter provides a realist systematic review focused specifically on monitoring of chronic disease in LMICs, using voice or text-messages.

Chapter 3



Photo 6. Mama Matlala's great-great-grandchild playing on his mother's phone (November 2013)

Chapter 3: The role of mobile text and voice communication in the monitoring of chronic disease management within public primary healthcare in resource-poor low- and middle-income country settings: a systematic realist review

3.1 Introduction to Chapter 3

The review synthesises evidence from low- and middle-income countries (LMICs) of mobile health (mHealth) communication interventions delivered as part of the management of long-term chronic diseases. The review is split into two parts.

Review a is a narrative review of reviews. The objective is to map the evidence for the effectiveness of mHealth for the management of chronic diseases in LMICs; in particular, in what context and with what design considerations are they effective. This Review a, informs the research question for Review b.

Review b is a realist review. The objective is to investigate whether mHealth text and voice interventions for the monitoring of chronic diseases in public primary care in LMICs are likely to achieve health benefits. This review tackles one of the gaps in knowledge identified in Review a: the lack of theoretical understanding of why mHealth interventions work or not for a particular population.

Chapter 3 addresses thesis Research Question 1:

Research Question 1.

What is the role of mobile phone communication in the monitoring of chronic disease management within public primary healthcare in resource-poor low- and middle-income country settings?

The research problem

The burden of chronic diseases is an escalating problem in LMICs (Abegunde *et al.*, 2007). Improving the prevention and management of chronic communicable and non-communicable diseases is a priority for primary care in public health systems (Beaglehole *et al.*, 2008). Chronic diseases are long-term, disruptive and often intrusive to individuals' everyday lives (Larsen & Lubkin, 2009). If managed well, the risk of morbidity and premature death are reduced (Gaziano & Pagidipati, 2013).

The management of a chronic disease is a dynamic process that can vary over time, depending on the disease aetiology and physiology (Schulman - Green *et al.*, 2012). Chronic diseases can often involve burdensome treatment and self-care regimens can be patient-centred (Shippee *et al.*, 2012; Kadirvelu *et al.*, 2012). Shippee *et al.* (2012:1045) proposed that treatment adherence, healthcare utilisation and health outcomes are influenced by the relationship between

‘the workload that is delegated to the patients by the healthcare providers (including self-care, managing treatment modalities, behaviour change and clinic visits) and the patient’s capacity to meet the demands of this workload (including physical and mental functioning, pre-existing health literacy and family and social support)’.

A patient’s workload and capacity can be reduced by social and environmental factors. This can lead to ineffective outcomes, notably ‘in the poor, who have a lower capacity to deal with ill-health’ (Oni *et al.*, 2014:4).

The management of chronic diseases is challenging in low-resourced health systems. Consistent and regular monitoring by the patient and health provider may be difficult to achieve due to poor access to healthcare, limited resources, distance to health facilities and low staff capacity (Goudge *et al.*, 2009; Gilson *et al.*, 2007). Also, patients who are proactive in managing their chronic disease are likely to have better health outcomes and well-being (Ekman *et al.*, 2012; Hudson *et al.*, 2012).

Chronic diseases management includes ‘routine monitoring to check on the progress or regress of the disease and the development of complications’ (Glasziou *et al.*, 2005:644). Monitoring may provide a signal for action (for example, a change in medication), for motivation to adhere to treatment or beneficial behaviours such as, healthy eating and exercise. Nurse-led primary

care is currently carrying the burden of this monitoring in many LMICs, including South Africa (Fairall *et al.*, 2012).

While, globally, health systems struggle to keep pace with the accelerating burden of chronic diseases, mHealth interventions are emerging to assist with the patient-centred management of chronic diseases (Nolte & McKnee, 2008). There is insufficient robust evidence of the impact and effectiveness of mHealth for long-term disease management and a lack of understanding of why mHealth interventions should work (or not) in LMICs (Mbuagbaw *et al.*, 2015; Krishna *et al.*, 2009; Free *et al.*, 2013; Velthoven *et al.*, 2012; Cole-Lewis & Kershaw, 2010; Fjeldsoe *et al.*, 2009; Bloomfield *et al.*, 2014; Catalani *et al.*, 2013; Bärnighausen *et al.*, 2011).

This review contributes to knowledge by understanding how the monitoring of chronic diseases via text and voice communication using mobile phones, can improve how a patient can monitor and interact with a remote health-worker (nurse/doctor/community health-worker). In this instance, the patient is a beneficiary (recipient) of an mHealth intervention from the health-worker/research group (provider). The intervention is conceptualised with the following components: the technology, the person using the technology, the intervention resources associated with the technology, and the associated behaviours of the user.

Inclusion and exclusion criteria common to both reviews

This review focuses on mHealth, not eHealth as this is too broad, often encompassing the use of computers and information systems, which is beyond the scope. Voice communication is included, as many patients in LMICs have limited vision, dexterity or literacy (Piette *et al.*, 2012b).

Both reviews consider two types of communication: mobile asynchronous text-messages and voice (automated or live) (Table 3). Both text and voice can be a one-way form of communication – such as, appointment reminders, where the patient is a passive recipient – or two-way communication – such as, support lines, where the patient is active in the receive–respond communication process. Two-way monitoring implies that the patient must observe and send the health professional information.

Table 3. Typology about mHealth for assisting with chronic disease’ monitoring (*Typology adapted from Marshall et al. (2013:7)*)

Type of Communication	Level of Interaction (One-way - passive)	Level of Interaction (Two-way - active)
Text messaging (text) also known as Short-Message Service (SMS)	-Appointment reminders (linked to retention to care) -Treatment reminders (adherence to medication) -Health promotion/motivational reminders for behaviour change (promotion of daily exercise)	-Appointment confirmation (reply to reminder) -Treatment compliance (send message that medication has been taken) -Patient monitoring (sends in measurements readings or explain current mood or state)

Voice services (automated or live)	-Automated health information lines (increase knowledge)	-Staffed information/support lines (patient asks a question and receives reply) -Patient monitoring (as above via speech)

The following is a list of databases searched and details the inclusion and exclusion criteria that applies to both reviews (Table 4).

Table 4. Databases, search terms and inclusion and exclusion criteria common to both Review a and b

Electronic database searched	Inclusion criteria for reviews	Exclusion criteria for reviews
The Cochrane Library, Cochrane register of controlled trials, Medline (Ovid) PubMed, Web of Science, Psych Info, Google Scholar, Knowledge for Health – mHealth Evidence database https://www.mhealthevidence.org	-Population: Patients with any chronic disease and all health professionals -Context: LMICs The reviews must be in English	-Reviews or studies set in high-income country are usually more advanced than resource-poor LMICs and often include landline telephones

Chronic diseases are the focus of this review rather than pregnancy. While pregnancy also needs monitoring for its duration, this period is brief compared to long-term chronic diseases. It would be difficult to combine monitoring of pregnancy and of chronic disease in one review. Also a review

by Sondaal *et al.* (2016) on the effect of mHealth interventions for improving maternal and neonatal care in LMICs has already been conducted. However, it is likely that the results from this review will be transferable to the digital monitoring during pregnancy.

The review concludes by presenting a theoretical framework for why mHealth interventions for the monitoring of chronic diseases may work given the context, the reasons by which mHealth interventions work, and the expected outcomes.

3.2 Study design for this review

Review a. Narrative review of systematic reviews of mHealth interventions for chronic disease management in LMICs. The objective is to provide a summary of evidence of effectiveness for mHealth intervention design considerations and knowledge gaps. The results inform the design of Review b.

This review questions:

- a) Is mHealth effective in the management of chronic disease in LMICs?
- b) What are the context and mHealth design considerations in the effective management of chronic diseases in LMICs?
- c) What further research is needed for mHealth interventions in the management of chronic diseases in LMICs?

Review b. Realist systematic review of mHealth for the monitoring of chronic disease in LMICs. The objective was to build a theoretical framework to identify context and mechanisms for effective outcomes of mHealth monitoring interventions. Then, to understand whether they are likely to achieve health benefits, as a mainstream primary care intervention within a public health system.

This review questions:

d) What are the mechanisms by which mHealth interventions improve chronic disease monitoring and in what context and for whom do they work?

Mechanisms in this review are defined as the reactions or responses to the resources available within an interaction process that leads to outcomes (Lacouture *et al.*, 2015:4). Mechanisms are contingent and conditional, and only ‘fire’ in particular contexts (Pawson & Tilley, 1997). The outcomes are the desired response to the intervention’s resources resulting from the participants’ reasoning (Dalkin *et al.*, 2015).

The two reviews are now reported consecutively.

3.3 Review a) mHealth interventions for the management of chronic diseases in LMICs: a narrative review of reviews

Methodology and methods for the narrative review of reviews

Narrative reviews are intended ‘to discuss the state of the science of a specific topic from a theoretical or contextual point of view’ (Rother, 2007). A

narrative approach was adopted because a summary of evidence was needed to inform the realist review.

A broad search for reviews on the management of chronic disease in LMICs using mHealth was undertaken (Table 4 and Table 5).

Table 5. Search terms and inclusion criteria for Review a and b

Search terms for systematic reviews	Inclusion criteria for systematic reviews
<p>Review a Patient* AND LMIC or low and middle income countr* AND chronic or chronic disease or long term condition* or chronic illness AND mobile phone* AND mobil* or cellular phone* or cell phone* or text or text messag* or SMS or short message servic* or voice AND self-manage* or self care NOT computer*</p> <p>Review b Patient and low- and middle-income countr* or LMIC or developing* and chronic disease and mobile phone* AND text messag* or SMS or voice and monitor* or self-monitor* and self-manage*</p>	<p>Review a -Review: must be about intervention effectiveness of mobile health communication (text and voice) for management of chronic disease -Study Design: only systematic reviews. Quality of the review (passed the CASP quality check) The reviews must be in English</p> <p>Review b -Study Design: Experimental design-RCT /feasibility pilots (qualitative/quantitative) -Empirical research: Process/health outcomes -Intervention: mobile health communication for monitoring of chronic disease</p>

Reference lists of relevant studies and personal collections of articles were also searched. This review used Chib's *et al.* (2015) rationale for not

including documents published before 2000 as mobile phones were not widely available in LMICs. Reviews were included even if only one section of the review met the inclusion criteria. In this instance, only the part of the review results relevant to the research questions were reviewed. Reviews included both qualitative and/or quantitative study designs.

Quality criteria

Reviews were checked for quality and fit using the Criteria for Systematic Reviews tool (CASP, 2010). Due to limited resources and the nature of a doctorate, the PhD candidate undertook the review alone. To quality check the process in both reviews, an independent quality checker was used to assess the extracted data to ensure rigour. Comparisons were made between the CASP assessments and following discussion, agreement was reached.

The following objectives guided what data was extracted from the systematic reviews, inline with Review b sub-questions a-c:

- Background information about each review: study setting, rationale, aims, research questions, sampling, data collection and analysis
- Summary of the strength of evidence for mHealth effectiveness of chronic disease management (relevant to review sub-question a and found in the results section of the included reviews). Even though

many of the reviews covered a range of topics, for this review of reviews, only results about management of chronic diseases were extracted.

- Results relevant to the design considerations necessary for mHealth to be effective (review sub-question b found in the discussion section of the reviews).
- Results relevant to the gaps in the evidence for the use of mHealth in the management of chronic diseases (review sub-question c on future research found in the discussion section of the reviews).

A thematic analysis of the results of the reviews was conducted. Themes were guided by the review's research questions. The results for each objective are reported separately.

Results for Review a

Figure 9 illustrates the sampling process. In total, 126 reviews were retrieved and, after exclusions, 23 reviews were included in Review a.

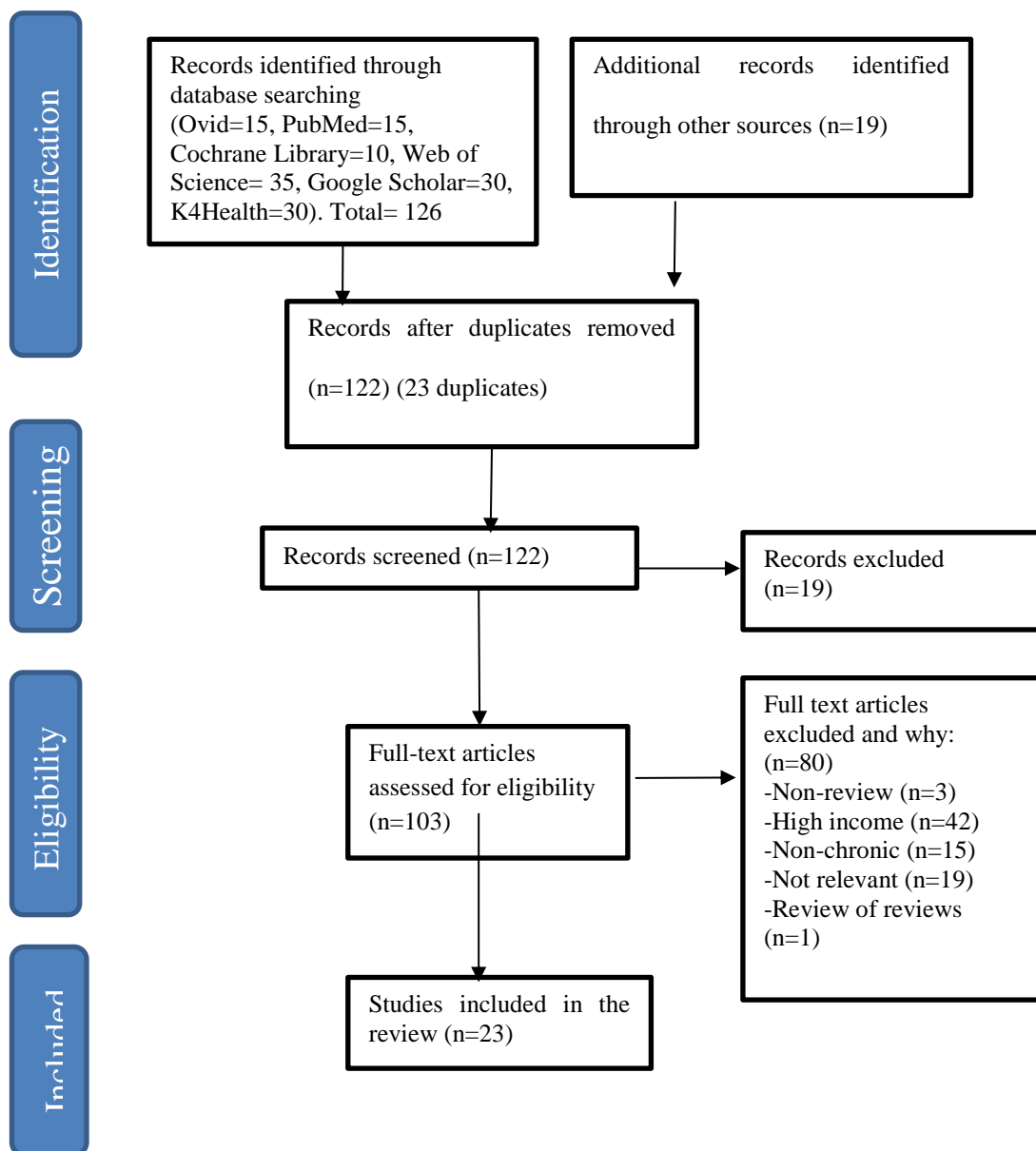


Figure 9. Flow diagram of review of reviews search and selection process (Review a)

The data extraction of Review a in Table 6, presents the characteristics of included systematic reviews (the first objective).

Table 6. Data Extraction of interventions in the reviews and outcomes, the key results and the first theme - an overall interpretation of intervention effectiveness (Review a)

Author, Date, Title	Setting, No. of studies/ Types of Interventions/Outcomes assessed	Relevant Results to the Review	Effectiveness of Chronic Disease mHealth Management: Good, Mixed or Evidence Unknown
Aranda-Jan <i>et al.</i> (2014) <i>Systematic review on what works, what does not work and why of implementation of mobile health (mHealth) projects in Africa</i>	Africa. Studies: 44 Patient follow-up and medication adherence, staff training, support and motivation, staff evaluation, monitoring and guidelines compliances disease surveillance and intervention monitoring data collection/transfer.	mHealth projects demonstrate positive health-related outcomes. Success based on accessibility, acceptance and low-cost of the technology, effective adaption to local contexts, strong stakeholder collaboration and government involvement. Main considerations for an effective mHealth project in African contexts: Good project design/Technology and resources/Involvement of stakeholders/Government eHealth and mHealth department.	Evidence Unknown Evidence remains poor, results are still project or setting-specific and questions regarding impact, scalability, increase coverage (e.g. different diseases, different settings, different target populations), cost-effectiveness and sustainability of the projects in Africa are yet to be addressed.
Beratarrechea <i>et al.</i> (2014) <i>The Impact of Mobile Health Interventions on Chronic Disease</i>	LMIC. Studies: 9 Impact of mobile technology (voice communication and SMS) on chronic disease outcomes in LMIC. Medication review, disease monitoring, appointment reminders, remote disease	In all attendance rate studies, SMS and mobile phone appointment reminders significantly improved attendance rates. Cellular phones are an established means of communication in developing countries. mHealth interventions deliver improved	Good The results for mHealth interventions showed a positive impact on chronic diseases in LMIC. mHealth was found to be cost-effective and had positive impacts on processes of care and clinical outcomes.

Outcomes in counselling, telephone helpline, clinical outcomes for patients with chronic
Developing educational programme, lifestyle disease. Processes of care outcomes were
Countries: A modification and motivation. Process improved, and this contributes to the cost
Systematic Review of care outcomes (that affect patient effectiveness of mHealth projects.
 care by improving healthcare delivery
 or patient–healthcare interactions) and
 clinical outcomes (intermediate
 outcomes or markers of disease
 severity, such as, haemoglobin A1c in
 diabetes)

Bärnighausen et al. (2011) *Interventions to increase antiretroviral adherence in sub-Saharan Africa: a systematic review of evaluation studies*
SAA. Studies: 26
 Investigating the effectiveness of ART adherence interventions in SSA. Hospital out-patient settings in urban areas in SSA and patients on ART. Interventions used behavioural/ cognitive/ affective components (some combining these). Treatment supporters providing emotional and instrumental adherence support.
 Medication use monitoring, data collection, treatment adherence, motivation and support

Adherence measured by viral suppressions/CD4 count/self-report of missing doses and pill count (subjective measures). The use of SMS increases treatment adherence and is a useful tool for disease monitoring in sub Saharan Africa.

Mixed
 Small effect sizes. Initial improvement in adherence may not persist over time.
Evidence Unknown
 Interventions are likely to significantly improve adherence, but further evaluation studies are needed to confirm intervention effects, determine effect duration, identify the modifying effects of the intervention design and context, and establish intervention cost-effectiveness.

Bastawrous and Armstrong (2013) <i>Mobile health use in low- and high-income countries: an overview of the peer-reviewed literature</i>	Includes LMICs. Studies: unknown. Multiple mobile phone based applications are available for healthcare workers and consumers.	Existing studies in LMICs lack the type of evidence that usually convinces funders of utility e.g. control arms and cost-effectiveness analyses.	Evidence Unknown Lacks evidence base
Betjeman et al. (2013) <i>Review Article: mHealth in Sub-Saharan Africa</i>	SSA. Studies: 18 mHealth in SSA. Medication adherence, health worker communication, emergency support, data collection, health education.	Short-term trials suggest that SMS reminders could be cost-effective way to improve medication adherence. Studies demonstrate that mHealth can improve and reduce the cost of patient monitoring, medication adherence, and healthcare worker communication, especially in rural areas. mHealth interventions show potential as a tool for increasing medication adherence and to maximise the effectiveness of healthcare workers. mHealth projects are technically feasible and effective in initial studies.	Evidence Unknown The current evidence is not strong enough to warrant large-scale implementation of existing mHealth interventions in SSA, but rapid progress of both infrastructure and mHealth-related research in the region could justify scale-up of the most promising programs in the near future. Areas of mHealth where the most promise has been shown are medication adherence and healthcare worker communication, though the evidence is not yet sufficient to warrant large-scale investment and policy change
Bloomfield et al.	Sub-Saharan Africa. Studies: 5	mHealth for NCDs in SSA appears feasible	Evidence Unknown

<p>(2014) <i>Mobile health for non-communicable diseases in Sub-Saharan Africa: a systematic review of the literature and strategic framework for research</i></p>	<p>Development of a framework to identify specific areas where evidence to support the efficacy of mHealth interventions in NCD management has been generated as well as those areas where such evidence is lacking. Access to mobile phones, clinical outcomes, peer support, lifestyle changes.</p>	<p>for follow-up and retention of patients, can support peer support networks, and use a variety of mHealth modalities. To address this gap between promise and evidence, the framework highlights mHealth strategies across the continuum of care for NCDs stratified by health systems challenges in SSA. Insufficient data found to show the efficacy of the use of mHealth in sub-Saharan Africa.</p>	<p>There is insufficient evidence to support the effectiveness of mHealth for NCD care in SSA. In summary, while there is great enthusiasm for the application of mHealth for NCDs in SSA, implementation is limited and evidence for a positive effect on health is sparse.</p>
<p>Catalani et al. (2013) <i>mHealth for HIV Treatment & Prevention: A Systematic Review of the Literature</i></p>	<p>Includes LMICs. Studies: 62 Describes the landscape of mHealth for HIV/AIDS and the evidence supporting the use of these tools to address the HIV prevention, care, and treatment cascade. Feasibility of mHealth intervention, treatment information, adherence, health education and data collection.</p>	<p>The review revealed evidence that mHealth tools support HIV programmatic priorities, including: linkage to care, retention in care, and adherence to antiretroviral treatment. mHealth tools facilitate alerts and reminders, data collection, direct voice communication, educational messaging and information on demand. Studies were mostly descriptive with a growing number of quasi-experimental and experimental designs. mHealth interventions have been shown to increase treatment adherence and attendance at appointments in LMIC settings.</p>	<p>Good Review found that patients receiving weekly SMS reminder messages had significantly improved antiretroviral adherence and rates of viral suppression compared with the control individuals. There is evidence that mHealth tools can improve linkage to care, retention in care, and adherence to ART. Evidence Unknown mHealth tools might be effective in addressing the HIV pandemic.</p>

		Feasibility pilot studies have shown that an mHealth intervention is well received by patients and is an option for improving healthcare outcomes.	
Chib et al. (2015) <i>mHealth Adoption in Low-Resource Environments: A Review of the Use of Mobile Healthcare in Developing Countries</i>	Developing countries. Studies: 53 Inputs, mechanisms and outputs (qual and quant evidence). Data collection, treatment adherence, qualitative – community health-worker opinion and patient opinion on mHealth programme.	Mechanisms of adoption and appropriation of technology at individual and sociocultural levels of analysis. Effectiveness measures of patient healthcare factors, defined as behaviour change or public health indicators within the beneficiary population. Patients and healthcare workers hold positive views towards the use of mobile phones in healthcare provision for chronic illness. They do not perceive SMS reminder messages to be a privacy intrusion.	Mixed The reviews found mixed results and lack the ability to show robust evidence.
Cole-Lewis and Kershaw (2010) <i>Text Messaging as a Tool for Behaviour Change in Disease Prevention and Management</i>	Global. Studies: 17 Provides an overview of behaviour change interventions for disease management and prevention delivered through text-messaging. Disease monitoring, symptom control.	Mobile phones are a useful tool for interventions seeking improvement in health outcomes and supports evidence that text-messaging is a useful tool for behaviour change interventions. Inconclusive results.	Mixed The majority of the studies (8) found evidence of short-term effects regarding a behavioural or clinical outcome related to disease prevention and management (diabetes).

<p>Deglise et al. (2012). <i>SMS for disease control in developing countries: a systematic review of mobile health applications</i></p>	<p>LMICs (India, South Africa and Kenya). Studies: 31 (17 on patient compliance). Examined SMS-supported interventions for prevention, surveillance, management and treatment compliance of communicable and non-communicable diseases in developing countries. SMS applications were evaluated and focused on HIV/AIDS. Prevention, surveillance, disease management, compliance.</p>	<p>Evidence that mobile phones are an appropriate and promising tool for disease control interventions in developing countries. 29 disease management interventions were used to monitor patients at homes or in clinics, support remote health-workers, facilitate communication between health-workers and patients, provide a way to record medical data, and for clinical diagnostic decision-support and Tele-medicine. Text messaging improved the process of care and was accepted by both health-workers and the targeted population. The majority of users and beneficiaries were familiar with mobile phones and SMS for private and professional utilisation, and the technology was reliable. Evidence unknown - breakdown of studies not shown.</p>	<p>Evidence Unknown While there was evidence suggesting that mobile phones are a promising channel for health communication and disease control, there was a lack of high quality SMS-based intervention studies in the peer-reviewed literature, especially those measuring clinical outcomes.</p>
<p>Free et al. (2013) <i>The Effectiveness of Mobile-Health Technology-Based Health Behaviour</i></p>	<p>Includes LMICs. Studies: 26 (Behaviour change: 14 and disease management: 37). The interventions targeted health behaviour change or disease management interventions.</p>	<p>Multifaceted mobile technology text-messaging interventions have been shown to increase adherence to antiretroviral medication in a low-income setting. A range of questions regarding the effects of mobile</p>	<p>Evidence Unknown There is currently insufficient high quality evidence of beneficial effects on clinical outcomes to warrant implementation of interventions for other areas of health behaviour</p>

<i>Change or Disease Management Interventions for Healthcare Consumers: A Systematic Review</i>	Primary outcomes were defined as any objective measure of health or health service delivery or use. Secondary outcomes were defined as the following: self-reported outcomes related to health behaviours, disease management, health service delivery or use, and cognitive outcomes. Treatment adherence/Improved clinical outcomes/ Disease monitoring Data collection.	technologies remain open to question including which functions are most effective (SMS, video, oral instruction, application software), which behaviour change techniques are effective, and whether the effectiveness of interventions is influenced by setting or participant demographics. Statistically significant improvement in clinical outcomes of a chronic disease with SMS patient monitoring.	change or self-management of diseases delivered by mobile technologies.
Gurman et al. (2012) <i>Effectiveness of mHealth Behaviour Change Communication Interventions in Developing Countries: A Systematic Review of the Literature</i>	Developing countries. Studies: 44 To determine how much evidence currently exists for mHealth BCC interventions in developing countries. The majority of BCC mHealth interventions were implemented in Africa (n=10) and Asia (n=4). HIV/AIDS (n=10) was most frequently addressed by interventions. Treatment adherence/ Qualitative questionnaire.	Studies did not consistently demonstrate significant effects of exposure to BCC mHealth interventions on the intended audience. The use of SMS for chronic disease management is acceptable in the target population. Confidentiality is an issue. SMS management has been shown to increase treatment adherence as part of a 2-way communication programme.	Evidence Unknown Although mHealth is viewed as a promising tool with the ability to foster behaviour change, more evaluations of current interventions need to be conducted to establish stronger evidence. mHealth is a promising field of study that may improve the effect of behaviour change programmes, but more studies need to be conducted with a greater emphasis on formative research and long-term evaluation.
Gurol - Urganci	Includes study from LMICs. Studies: 8	Mobile text reminders had similar impact to phone call reminders but were cheaper.	Mixed Low to moderate quality evidence included in

<p>et al. (2013) <i>Mobile phone messaging reminders for attendance at healthcare appointments (Review)</i></p>	<p>The effects of mobile phone messaging reminders for attendance at healthcare appointments (Appointment attendance). Secondary objectives include assessment of costs; health outcomes; patients' and healthcare providers' evaluation of the intervention and perceptions of safety; and possible harms and adverse effects associated with the intervention.</p>	<p>Adverse events such as, loss of privacy, data misinterpretation, or message sending failure not reported. Appointment attendance is increased with SMS use versus no reminder or a postal reminder.</p>	<p>this review shows that mobile phone text-messaging reminders increase attendance at healthcare appointments compared to no reminders, or postal reminders.</p>
<p>Hall et al. (2014) <i>Assessing the impact of mHealth interventions in low- and middle-income countries - what has been shown to work?</i></p>	<p>LMICS. Studies: 76 (20 on client education and behaviour change). There is a growing evidence base for the efficacy of mHealth interventions in LMICs, particularly in improving treatment adherence, appointment compliance, data gathering, and developing support networks for health-workers. Treatment adherence, disease surveillance, data collection.</p>	<p>The quantity and quality of evidence is still limited. Found that client education and behaviour change was the most represented domain. A lot of evidence is anecdotal evidence. mHealth interventions can show positive health-related outcomes, especially in relation to treatment adherence. Projects can be adapted to suit local context and suit the infrastructure of LMIC.</p>	<p>Evidence Unknown Too broad a review to gather effectiveness of management interventions. They are just in agreement that mHealth is clearly becoming an important concept in LMICs, but as yet there is very limited hard evidence on its effects within health systems.</p>
<p>Higgs et al. (2014) <i>Understanding the Role of mHealth</i></p>	<p>LMICS: Studies: 15 Child survival using a range of mHealth strategies. Those that influences or</p>	<p>Sustainability evidence is weak. There is a paucity of evidence demonstrating behavioural changes.</p>	<p>Evidence Unknown</p>

<p><i>and Other Media Interventions for Behaviour Change to Enhance Child Survival and Development in Low- and Middle-Income Countries: An Evidence Review</i></p>	<p>modified behaviours contributing to child health outcomes. The studies fell into five intervention categories: we focused on results from - provider behaviours/ patient medication compliance/patient compliance with healthcare appointments. Treatment adherence, appointment attendance, support and motivation.</p>	<p>SMS communication can improve treatment adherence and appointment attendance in a chronically ill population in an LMIC. Timing of SMS reminders can affect efficacy (weekly showed significant improvement vs. daily).</p>	<p>mHealth interventions have sufficient evidence to make topic-specific recommendations for boarder implementation and scaling.</p>
<p>Horvath et al. (2012) <i>Mobile phone text-messaging to help patients with HIV infection take their antiretroviral medications every day</i></p>	<p>Kenya: Studies: 2 To determine whether mobile phone text-messaging is efficacious in enhancing adherence to ART in patients with HIV infection. Treatment adherence. Motivation and support. Clinical outcomes. Quality of life.</p>	<p>Short weekly text-messaging was associated with a lower risk of non-adherence at 12 months. No significant difference between weekly short and long messages. Text-messages did not reduce the risk of non-adherence compared to standard care.</p>	<p>Good In meta-analysis of both trials weekly short to long messages was associated with a lower risk of non-adherence at 48-52 weeks. There is high-quality evidence from the two randomised controlled trials that mobile phone text-messaging at weekly intervals is efficacious in enhancing adherence to ART.</p>
<p>Lall and Prabhakaran (2014)</p>	<p>LMIC. Studies: unknown Primary care diabetes – development of self-management skills using</p>	<p>Has the potential to deliver self-management support and decision-support.</p>	<p>Good Interventions involving mobile phone messaging and reminders using phones are</p>

<i>Organisation of primary healthcare for diabetes and hypertension in high, low and middle income countries</i>	innovation such as, mobile phone messaging. Medication compliance. Self-management/decision-support.	SMS reminders can increase adherence to treatment regimens. Use of weekly SMS sowed improved clinical outcomes in patients managing a chronic condition. Text-message did not reduce the risk of non-adherence.	important and have shown beneficial results. Mixed The evidence for mobile phone messaging and reminders using phones are important and have shown beneficial results - is still limited and robust trials are needed to establish its effectiveness, especially in LMICs
Mbuagbaw et al. (2013) <i>Mobile texting to improve adherence to ART</i>	Kenya and Cameroon (SSA). Studies: 3 Analyse the effects of text-messaging versus usual care in improving adherence to antiretroviral therapy (ART) in people living with HIV using individual patient data meta-analysis.	Text messaging has a significant effect on adherence to ART, and this effect is influenced by level of education, gender, timing (weekly verses daily) and interactivity.	Good Test messaging has a significant effect on adherence to ART. The use of interactive weekly text-messaging to boost adherence to ART, especially in clients with at least a primary level of education was recommended.
Nglazi et al. (2013) <i>Mobile phone text-messaging for promoting adherence to anti-tuberculosis treatment: a systematic review</i>	LMIC. Studies: 4 Aims to synthesise current evidence on the effectiveness of SMS interventions in improving patients' adherence to TB treatment. The primary outcome was treatment adherence considering TB cure, successful completion of TB treatment and drug resistance development as proxies for adherence	Findings indicate that interventions have a potential for use to improve patient adherence to TB treatment, though the evidence is inconclusive. Very little data on this topic. Use of SMS reminders increased attendance at clinic, showed improved patient satisfaction with their healthcare provider and increased rates of TB cure,	Mixed Overall, the included studies suggest that patients receiving mobile phone text-messaging interventions had rates of adherence to TB treatment comparable to or higher than those receiving no intervention. Therefore, the findings provide mixed evidence for the effectiveness of mobile phone text-messaging interventions designed to promote adherence to

	and secondary: patient satisfaction with the SMS intervention. Treatment adherence, therapy reminders, appointment attendance, patient satisfaction with SMS and clinical outcome.	however half of the studies showed no improved outcomes vs. controls.	TB treatment. Evidence Unknown There is a paucity of high-quality data on the effectiveness of SMS interventions for improving patients' adherence to tuberculosis treatment. The quality of the available evidence on the use of SMS interventions to promote patient TB treatment adherence is low. Inconclusive evidence of efficacy implies that this intervention should not yet be scaled up in TB programmes outside research settings.
Peiris et al. (2014) <i>Use of mHealth Systems and Tools for Non-Communicable Diseases in Low- and Middle-Income Countries: a Systematic Review</i>	LMIC. Studies: 24 Examined the ability of mHealth interventions to improve healthcare quality in LMIC settings for NCD management and prevention. Call for comparative effectiveness studies examining mHealth. Patient education, disease management, data collection	There were limited literature reporting clinical effectiveness, costs, and patient acceptability, and none reporting equity and safety issues. Although the studies that have reported effectiveness are encouraging, few have examined outcomes across multiple dimensions of healthcare quality, and none have looked at equity and safety issues. mHealth for non-communicable disease management is a relatively unexplored area.	Evidence Unknown Much remains unknown about whether and how this will be fulfilled therefore the current evidence base is insufficient.
Riley et al. (2011) <i>Health behaviour</i>	Includes LMICs. Studies: 10 Studies use of mobile technology to improve	Despite the simple nature of these appointment adherence interventions and	Good Outcomes from the mobile disease management

<i>models in the age of mobile interventions: are our theories up to the task?</i>	treatment adherence. 20 studies on disease management. The study aims to determine how health behaviour theories are applied to mobile interventions. This is a review of the theoretical basis and interactivity of mobile health behaviour interventions. Clinical outcomes, medication adherence, appointment attendance, health education, chronic disease management and health behaviour theories.	their lack of interactivity and theoretical basis, most resulted in a significant increase in appointment adherence. Increase in appointment attendance in groups using mHealth interventions. No studies based on health behaviour theories.	studies were generally positive and statistically significant.
Sahu et al. (2014) <i>Role of Mobile phone technology in health education in Asian and African countries: a systematic review</i>	Asian and African countries. Studies: 13. The objective of the review was to explore the role of mobile phone technologies in delivering health education (includes remote monitoring health awareness programmes. Mobile healthcare offers new opportunities for patients and healthcare professionals for a share decision-making and facilitate delivery of tailored healthcare interventions. Clinical outcomes, health education, medication adherence.	Results of the present review showed that mobile phone technologies can be a possible solution to improve healthcare outcome. Mobile phones were found to be both convenient and effective in health monitoring, self-management of chronic diseases, medication adherence and public health awareness. Mobile phones can be a positive intervention to improve health outcome, convenient and effective for health monitoring.	Evidence Unknown Effectiveness unknown but viable as a possible solution.

Velthoven et al. (2012). <i>Scope and effectiveness of mobile phone messaging for HIV/AIDS care: A systematic review</i>	Includes LMICs. Studies: 21 (Qual and Quant). The objective of this mixed method review was to assess the scope, effectiveness, acceptability and feasibility of the use of mobile phone messaging for HIV infection prevention/treatment/care. Appointment reminders/medication adherence/data collection, healthcare professionals communication.	Mobile phone messaging was perceived as an acceptable way to receive information and to communicate with health-workers. Findings regarding effectiveness from those studies must be carefully interpreted because of the weaknesses in their design. Improved outcomes for patients adhering to ART in mHealth intervention group vs. controls. SMS reminders were viewed favourably in the target population.	Mixed Found limited evidence on the effectiveness of mobile phone messaging for HIV care. Evidence Unknown Absence of evidence about effectiveness should not be treated as evidence of no effect.
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Overall, the 23 systematic reviews varied in quality and in the number of studies they reviewed. The types of interventions the reviews covered included both voice and text interventions that differed in duration, content and type of interaction with a health professional. Some interventions were patient-initiated and others were provider-initiated. The next section will respond to sub-question a).

The effectiveness of mHealth in the management of chronic disease in LMICs

The results from many of the reviews suggest that evidence for the effectiveness of mHealth interventions in chronic diseases management is still relatively unknown in LMICs (Aranda-Jan *et al.*, 2014; Betjeman *et al.*, 2013; Deglise *et al.*, 2012; Bloomfield *et al.*, 2014; Gurman *et al.*, 2012) (Nglazi *et al.*, 2013; Peiris *et al.*, 2014; Sahu *et al.*, 2014).

Several reviews suggested that robust evidence cannot be demonstrated because the effect sizes were small and the quality of the studies were moderate (Chib *et al.*, 2015; Gurol - Urganci *et al.*, 2013).

Text-messaging does have significant effect on adherence to ART for people with HIV. In particular, when an intervention is multifaceted (a reminder text-message and another component such as, a health promotion message). Text

messaging, as a tool to improve adherence to antiretroviral therapy is positively influenced by the level of education, timing (weekly versus daily) and patient–provider interaction (Mbuagbaw *et al.*, 2013; Horvath *et al.*, 2012; Catalani *et al.*, 2013; Pop-Eleches *et al.*, 2011; Bärnighausen *et al.*, 2011; Lall & Prabhakaran, 2014).

There is some evidence of short-term effects on processes of care and behavioural and clinical outcomes. For example, an increase in the frequency of blood glucose monitoring and reporting via text-message in diabetic young adults (Cole-Lewis & Kershaw, 2010; Free *et al.*, 2013; Beratarrechea *et al.*, 2014).

The sustained effects over a long period of time were unknown in all of the reviews. None of the studies reviewed were longitudinal. It is unclear whether text or voice interventions for chronic disease management are beneficial over the long-term.

It is suggested that stronger evidence is necessary to warrant large-scale implementation (Peiris *et al.*, 2014). The causal pathways that link mHealth to improved chronic disease outcomes require further investigation (Bloomfield *et al.*, 2014; Nglazi *et al.*, 2013; Gurol - Urganci *et al.*, 2013).

mHealth interventions for chronic disease management are effective if attention is paid to their design and implementation.

This next section will address the review sub-questions b) and c).

Design considerations for effective chronic diseases monitoring using mHealth

The following five themes were identified: text/voice design considerations, the health system within which it is being used, characteristics of the community, contextual prerequisites and lastly mHealth as an addition to standard care.

1. The design of the asynchronous mobile text/voice communication interventions for chronic diseases management

- Interventions are more likely to work if there is two-way communication (Cole-Lewis & Kershaw, 2010; Gurman *et al.*, 2012).
- The timing of the message or voice call is important (Riley *et al.*, 2011; Gurman *et al.*, 2012; Deglise *et al.*, 2012; Gurol - Urganci *et al.*, 2013).
- The message content must be a mix of tailored and generic messages with careful consideration of the framing of the message. The content must adapt over time depending on the course of the disease (Gurman *et al.*, 2012; Deglise *et al.*, 2012).

- Attention to message-fatigue of the end-user must be considered over time (Mbuagbaw *et al.*, 2013).
- The frequency and/or intensity of the messages sent (dose-response) and duration of the communication may only have short-term effects (Gurman *et al.*, 2012; Free *et al.*, 2013; Riley *et al.*, 2011).
- The length of the message (the shorter the better to prompt action) must be considered (Deglise *et al.*, 2012).
- The enabling of shared decision-making between patient and provider is of importance (Sahu *et al.*, 2014).

2. Characteristics of the health system within which it is being used

A relevant person should be available to respond to provide feedback (Deglise *et al.*, 2012).

3. Characteristics of the community: social values and norms and ethical concerns

- Phone ownership and power over the phone and, an assumption that a patient will understand the message (level of education/literacy). (Velthoven *et al.*, 2012; Gurman *et al.*, 2012).
- Text-messages must be written in the most appropriate way for the population (Velthoven *et al.*, 2012; Gurman *et al.*, 2012).

4. Contextual prerequisites (which may be a barrier if not in place) to be considered

- Infrastructure such as, health systems' limitations, human capital and resources (Cole-Lewis & Kershaw, 2010).
- Availability of electricity to charge a mobile phone (Deglise *et al.*, 2012; Velthoven *et al.*, 2012).
- Mobile networks, often limited and inconsistent in remote areas (Deglise *et al.*, 2012; Velthoven *et al.*, 2012).
- Capability to use and understand technology (to send/receive messages) as part of the care regimen (Velthoven *et al.*, 2012; Gurman *et al.*, 2012).
- Literacy, level of comprehension and patient confidentiality must be considered (Deglise *et al.*, 2012; Cole-Lewis & Kershaw, 2010; Velthoven *et al.*, 2012).
- The current context of the individual – time, location, social environment, psycho-physiological state (the patient's current and past behaviour and situational context) and sociological factors such as, culture and gender must be accounted for (Free *et al.*, 2013; Beratarrechea *et al.*, 2014).
- The maintenance costs of the technology, the purchasing power of phone credit by the user or provider and the relevance of mobile communication to patients' lives must be considered (Deglise *et al.*, 2012; Velthoven *et al.*, 2012).

5. mHealth as an addition to standard care

The mHealth intervention must be complementary to face-to-face or routine care or other counselling (Riley *et al.*, 2011; Deglise *et al.*, 2012).

The gaps in evidence for the use of mHealth communication in the management of chronic diseases in LMICs

The gaps in knowledge suggested in the reviews are summarised thematically in Table 7.

Table 7. Gaps in the research evidence for mHealth used for chronic disease management

Theme of knowledge gap	Review reference
Sustainability of mobile monitoring	(Beratarrechea <i>et al.</i> , 2014)
Lack of theoretical understanding of why mHealth interventions work for a particular population	(Catalani <i>et al.</i> , 2013) (Chib <i>et al.</i> , 2015) (Velthoven <i>et al.</i> , 2012) (Bärnighausen <i>et al.</i> , 2011) (Cole-Lewis & Kershaw, 2010) (Riley <i>et al.</i> , 2011)
Lack of evidence of sustained effect	(Free <i>et al.</i> , 2013) (Deglise <i>et al.</i> , 2012) (Gurman <i>et al.</i> , 2012) (Betjeman <i>et al.</i> , 2013)
Lack of evidence of impact on health outcome overtime	(Sahu <i>et al.</i> , 2014)
Need for more Randomised Control Trials (RCTs) conducted to test the efficacy of the intervention in more-representative samples	(Nglazi <i>et al.</i> , 2013) (Beratarrechea <i>et al.</i> , 2014) (Velthoven <i>et al.</i> , 2012) (Lall & Prabhakaran, 2014)
mHealth interventions need to be monitored and evaluated including use of outcome measures	(Hall <i>et al.</i> , 2014) (Velthoven <i>et al.</i> , 2012) (Catalani <i>et al.</i> , 2013)

Equity issues for vulnerable/minority groups	(Riley <i>et al.</i> , 2011) (Hall <i>et al.</i> , 2014) (Aranda-Jan <i>et al.</i> , 2014)
Risks/ harms/ safety/ legal/ ethics/ confidentiality issues	(Velthoven <i>et al.</i> , 2012) (Deglise <i>et al.</i> , 2012) (Gurol - Urganci <i>et al.</i> , 2013)
Cost-effectiveness	(Gurman <i>et al.</i> , 2012) (Cole-Lewis & Kershaw, 2010) (Peiris <i>et al.</i> , 2014) (Sahu <i>et al.</i> , 2014) (Free <i>et al.</i> , 2013) (Deglise <i>et al.</i> , 2012)
Consumer satisfaction/ acceptability/ user-perceptions/ limitations of text-message	(Gurol - Urganci <i>et al.</i> , 2013) (Higgs <i>et al.</i> , 2014)
Complementary functions of the mobile phone or alternative technologies	(Beratarrechea <i>et al.</i> , 2014)

Conclusion for Review a

There is evidence for the effectiveness of mHealth in improving the management of chronic diseases in LMICs, particularly for HIV patients. Not one review focused specifically on monitoring. However most reviews suggest the need for more evidence. There is a lack of theoretical understanding of why mHealth interventions work, even where reviews consider design of the interventions.

The quantity and quality of evidence are still limited for chronic disease mHealth management (Hall *et al.*, 2014). Text messages sent to improve adherence to antiretroviral medication can be effective. Two reviews identified the potential for mHealth interventions to improve the monitoring

of patients with chronic diseases in LMICs. For example the monitoring of patient health and disease status and, the adjustment of medication dosage (such as, insulin or asthma medications) to improve feedback and the monitoring of health outcomes (Free *et al.*, 2013; Cole-Lewis & Kershaw, 2010). Mobile phone appointment reminders significantly improved attendance rates in a chronically ill population in an LMIC (Beratarrechea *et al.*, 2014; Higgs *et al.*, 2014). Short, weekly text-messaging was associated with a lower risk of non-adherence at 12-months (Horvath *et al.*, 2012; Mbuagbaw *et al.*, 2013). Short-term trials suggested that text reminders could also be a cost-effective way to improve medication adherence (Betjeman *et al.*, 2013; Lall & Prabhakaran, 2014). Mobile text reminders had an impact similar to phone call reminders but were cheaper (Gurol - Urganci *et al.*, 2013). Another significant finding was mHealth interventions have the potential to deliver self-management and decision support. Mobile phones can be a positive intervention for improving health outcomes and can be convenient and effective for chronic disease monitoring (Sahu *et al.*, 2014).

This narrative review has established the poor use of theoretical science in the design of mHealth interventions for chronic disease management. There is a lack of understanding of how mHealth interventions for chronic disease management work or do not work in certain contexts and for certain patients and cause certain outcomes. Combined with this, there is a distinct paucity of

intervention evidence focusing particularly on the *monitoring* of chronic disease as part of management. This is likely either to be because there is a scarcity of implemented mHealth text and voice interventions or because trials and pilots are still in progress or unpublished.

A strength of Review a is that it is possibly the first review of reviews to summarise the evidence of the effectiveness of text and voice mHealth management interventions in LMICs. However, a potential limitation was that the reviews included many types of mHealth technologies for purposes other than just disease management. Although the extracted data were specifically on management, the results had to be interpreted carefully to ensure that studies on disease prevention, for example were not included.

Combined, the reviews suggest further research. It was decided that the lack of evidence on mobile monitoring and the theoretical knowledge of mHealth interventions would be the focus of Review b as the selected research gap. This is because it is achievable in a review and more relevant to this thesis than equity issues, risks and consumer satisfaction, though these are important. Also, not all topics in need of future research can actually be achieved in a review. For example, RCTs and evaluations of outcome measures, such as, cost-effectiveness and the engagement and retention of

patients relative to effects sustained, require primary studies to be conducted. Finally, alternative technologies were outside the scope of this review.

The reasons for undertaking the next review are as follows. At least six of the reviews highlighted the lack of understanding of theory models and mechanisms of change. The authors suggest that future studies should explicitly describe the theoretical constructs being targeted by mHealth interventions. Many empirical studies did not provide a theoretical explanation for technology adoption and how the intervention works along the entire pathway (Chib *et al.*, 2015). Many of the causal pathways are unknown. Therefore, a greater understanding of theoretical frameworks and programme logic will strengthen the mHealth evidence-base (Catalani *et al.*, 2013). In particular, by defining why and how interventions work in certain circumstances and why they remain ineffective under other conditions (Velthoven *et al.*, 2012).

To address the poor understanding of how mHealth monitoring interventions work, a realist review was conducted to search for empirical studies on monitoring in LMICs.

3.4 Review b) mHealth interventions for monitoring of chronic diseases in LMICs: a realist review

Introduction to the realist review

A realist review draws on both theory and empirical research from across multiple disciplines (Wong *et al.*, 2011). This review aims to:

- (i) *Refine programme theory (an explanation) by establishing the mechanisms by which mHealth monitoring interventions for chronic diseases do or do not work (review sub-question d).*
- (ii) *Test these mechanisms (that cause change or outcome) and ‘search for causality’ (Wong et al., 2013).*
- (iii) *Develop recommendations for how the findings of the study can be used to assist implementers in developing monitoring interventions in specific populations, considering the mechanisms of change.*

The realist methodology is described, followed by the method of the systematic search process.

The realist review methodology

Realist synthesis is still an emerging methodology that seeks to understand how the intervention (mHealth monitoring) works in specific contexts (low-resource) and what outcomes (enhanced communication to improve health) may result. There is growing interest in ‘theory-driven, mixed-method

approaches to systematic reviews as an alternative to conventional Cochrane style reviews' (Greenhalgh *et al.*, 2011:1). A common purpose of 'policy-friendly' realist approaches is to 'make sense of heterogeneous evidence about complex interventions applied in diverse contexts in a way that informs policy' (Greenhalgh *et al.*, 2011:1; Otte-Trojel & Wong, 2016:277).

Review b aids the development of a programme theory, an explanation of the 'ideas and assumptions underlying how, why and in what circumstances complex social interventions work' (Dalkin *et al.*, 2015:3) and how the planners of the intervention expect it to reach its objective(s).

The purpose of searching the literature is to identify a body of empirical evidence to elucidate a chain of events or programme theory and then test it (Wong *et al.*, 2013). The goal is not to seek every relevant article in the field of enquiry but to obtain a representative sample (of both successful and unsuccessful interventions) to test the proposed programme theories. This process can help to find the important aspects such as, the mechanisms of a complex intervention that might have made it work or not.

Weiss (1997) describes mechanisms not as the actual intervention (which is part of the resource) but as the 'response' it triggers from stakeholders (patients) and the resulting outcomes. Dalkin *et al.* (2015:4) has extended

Pawson and Tilley's (2004) realist formula by including resource and reasoning elements to the configuration:

$$(\mathbf{Mechanisms} \text{ (Resources)} + \mathbf{Context} + \mathbf{Mechanisms} \text{ (Reasoning)}) = \mathbf{Outcome}$$

This formula assumes that intervention resources are introduced in a context, thus enhancing a change in reasoning. This alters the behaviour of the intervention's participants, leading to outcomes. Intervention resources and the resources within the patient's pre-existing contexts are combined. Multiple mechanisms can be hierarchical and are necessary for an intervention to work with the desired effect (Davey *et al.*, 2015). Mechanisms can be described at the micro-, meso- or macro-levels. Pawson *et al.* (2004:18) assert there are no 'new' ideas, only a certain number of intervention types. Similarly, humans only behave in a certain number of ways. Thus there are a limited number of mechanisms that can cause a change, with some being more important than others.

Pawson and Tilley (1997) agree that mechanisms are identified at the level of human reasoning and are considered on a continuum of activation. As humans, we are externally constrained in our actions. However, part of 'human agency is the choice to attempt to change the initial conditions that bear down on us' (Dalkin *et al.*, 2015:2). The reasoning of human agency is the person's behaviour or choice, dynamically influenced by the distal

structural contingencies, the external and proximal biological and ‘internal desires and drivers’ (Glass & McAtee, 2006:1650). Individuals make decisions (in part determined by human agency) about whether or not to use resources provided by the intervention in question, under the influence of the context in which the intervention was situated (Wong *et al.*, 2013).

In the results, a section on the CMOc is presented and then a section on theory is reported. Theory is used as an explanation with the aim to understand how a patient’s reasoning can change from understanding the information, to taking effective action (the monitoring) given the patient’s and intervention’s resources (Dalkin *et al.*, 2015).

Methods for the realist review

A realist enquiry seemed the most appropriate to answer thesis Research Question 1. This review followed four stages described in Box 4.

The stages of a realist review

Although the stages are presented sequentially, they overlap and are iterative because of the focus in refining theories.

Define the scope of the review

Identify the question/clarify the purpose of the review.

Search for and appraise the evidence

- a. Background search to understand the extent and nature of the literature.
- b. Progressive focusing to identify the programme theories.
- c. Search for empirical evidence to test a subset of these theories.
- d. Final search once the synthesis is almost complete.

Search Strategy

Purposive sampling was used with the aim of retrieving papers purposively to answer specific questions or test particular theories. The refining of the inclusion criteria occurred in light of emerging data (unlike Cochrane reviews, where this is predefined). The same notion of theoretical saturation, as in qualitative research, was used to question whether the search was still finding new knowledge.

Extract and synthesise the findings

Explain what the emergent findings are.

Programme theories (how the study authors think their intervention works) were identified and from this a new programme theory is proposed from all the included studies, by finding the mechanisms that caused the change.

The high-level literature used concepts, domains and theories to support the mechanisms that mobile monitoring interventions should include.

4. Draw conclusions and make recommendations

Results on the review: combine both theoretical thinking and empirical evidence.

Design a conceptual framework of review findings.

Box 4. A summary of the stages of a realist review guided by mapping process of a realist review as described by Pawson *et al.* (2004:29) and Rycroft-Malone *et al.* (2012:3)

Defining the scope of the review was undertaken in Review a.

Search processes, evidence appraisal and data extraction

First a systematic search was conducted for empirical studies on mHealth interventions (text and voice) used for the monitoring of chronic diseases in LMICs. Snowballing of each review's reference list was also used to extend the search. To get a maximum sample, broad inclusion criteria were set and a range of databases was searched. This review included all types of chronic

diseases. Realist reviews do not have a hierarchy of evidence, and data to test theory comes from qualitative and quantitative research designs.

Search results were combined from across the databases, duplicates removed and citations screened against the inclusion criteria. Results were extracted from each empirical study's results section. This included the intervention's description, objective, outcomes and a summary of the results by the study authors. The quality of the studies identified through systematic review was assessed using qualitative and cohort Critical Appraisal Skills Programme (CASP, 2010) tool.

Following data extraction, the Context–Mechanisms–Outcome configurations (CMOc) from each empirical study was sought (Appendix 2). Empirical results informed the choice of high-level theory. Theories were then used to test the mechanisms from each study's CMOc. Theories utilised were often from other disciplines such as, psychological and cognitive-behavioural theory. Examples explain what the interventions were doing mechanistically. If the aim of the study was to assist with patients' motivation towards the chronic disease monitoring, then theories pertaining to motivational theories (psycho-cognitive theory) were sought. The CMOc for each study are summarised in Table 11 alongside theoretical domains (Michie *et al.*, 2011). The refined theories can then help to determine whether mHealth

monitoring can work, by also considering the design aspects of an mHealth intervention (findings from Review a).

In addition to high-level theory, concepts and domains were used to crystallise the mHealth monitoring mechanisms (Table 11). Vassilev *et al.* (2015) identified three concepts of why mHealth interventions work: *Relationships*, *Fit* and *Visibility* (Table 8).

Table 8. High-level concepts from a tele-monitoring review by Vassilev *et al.* (2015:23), adapted in this review to be used for mHealth interventions

Concepts	Explanation
Relationships	<i>Relationships</i> provide support (professional, peer, clinical and social) for behaviour change and provide opportunities for professional feedback, which reinforce positive or facilitate behaviour change.
Fit	<i>Fit</i> explains that mHealth interventions are those that are well integrated into everyday life and healthcare routine, and easy to use, compatible with patients' existing environment, skills and capacity and that do not significantly disrupt patients' lives and routines.
Visibility	<i>Visibility</i> makes the disease apparent and allows for opportunities to share and engage information facilitating and mediating knowledge and motivations, which are inextricably linked to the actual tasks of self-management. Visibility operated by enabling feedback, which reinforced positive or required behaviour change by providing incentives, reminders and behaviour prompts to action.

Vassilev *et al.* (2015:21) argued that user-skills and physical capacity to understand how an intervention may be enhanced and embedded into a set of 'relationships and cultural practices' for both patients and health professionals is essential.

Michie *et al.* (2013:7) designed the ‘COM-B Domain Model’ (Figure 10). In this review, this model was used to describe the *Capabilities (C)*, *Opportunities (O)* and *Motivations (M)* necessary for *Behaviour (B)* that occur in mobile monitoring interventions (Table 12). The COM-B model is one of the few behavioural frameworks to include domains relevant to mobile technology.

Capability – Opportunity – Motivation = Behaviour (COM-B)

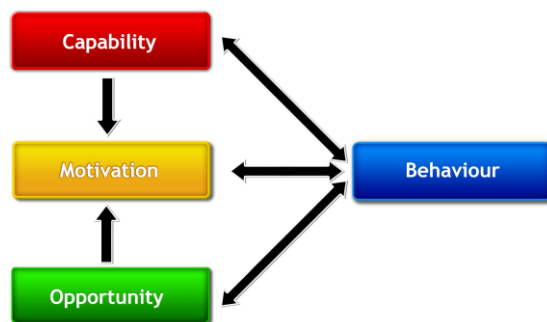


Figure 10. COM-B model for understanding behaviour (Michie *et al.*, 2013:4)

The COM-B model was used to illustrate and apply each domain in relation to monitoring, using a text or voice intervention (Table 12). This high-level theory was then applied to mHealth by taking the empirical study examples to suggest why each domain is necessary for the mHealth intervention to work.

The refined programme theory is then presented using a novel framework.

Results for Review b

This is the third stage of the review, in which the findings are extracted and synthesised. Review b is divided into two results sections: **1) empirical** and **2) theory**.

Section 1: Results of empirical studies on monitoring

The search retrieved 32 studies, 11 of which were eligible to be included (Figure 11).

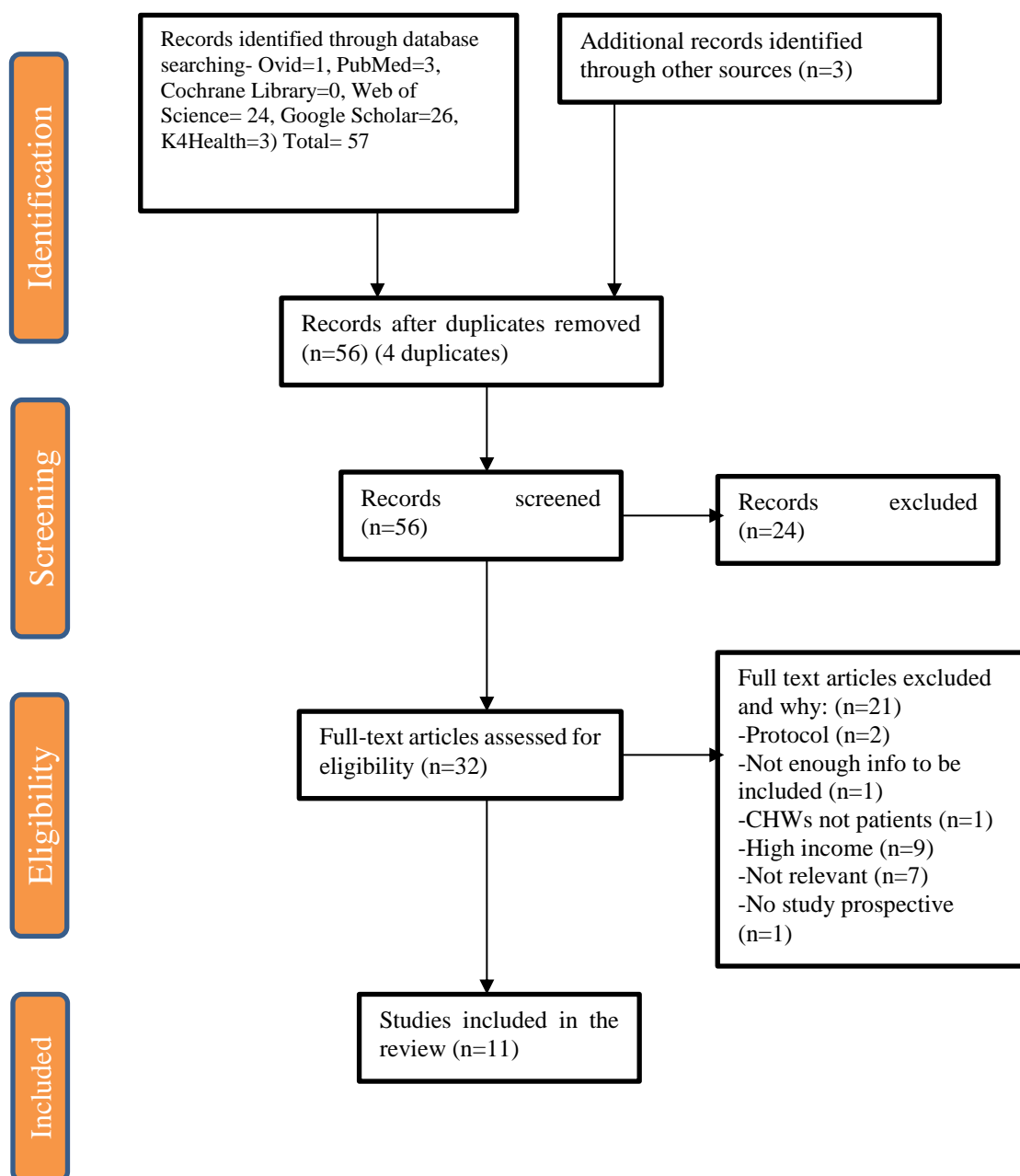


Figure 11. Flow diagram of the realist review search and selection process (Review b)

In summary, the empirical studies used either qualitative or quantitative methods and were trials and feasibility studies conducted in Asia, South

America, the Caribbean Basin and Africa (countries: India, Bolivia, Honduras, Mexico, South Africa, Kenya and Cameroon). The studies predominately included TB, HIV, diabetes and hypertension (Table 9). Findings were interpreted within the context of poor socio-economic environments as suggested by the study authors.

In all 11 studies, the exchange of digital information was two-way and was initiated by the patient or healthcare provider. The purpose of the monitoring interventions varied such as, information exchange or behavioural change, by using a buddy system, automated messaging or supportive counselling services. Three studies provided the patient with a home monitoring kit and/or phone and the other patients used their own mobile phone.

Table 9. Data extraction of the description of the empirical studies, their intended objective and outcome, country, disease and design and the summary of results (Review b)

Author, Date, Title, Study Name	Description of intervention	Purpose/ objective of study (What is the intervention meant to do)	Intervention Outcomes (What is the intervention measuring?)	Country, Disease Type, Design & Target Population	Summary of Results by the Authors
DeSouza et al. (2014) <i>Mobile Phones: The next Step towards Healthcare delivery in Rural India</i>	Acceptability study of mobile phones in management of chronic illness using a questionnaire to ascertain phone usage patterns and acceptability of healthcare interventions delivered via mobile phones including 5 domains (i) basic functionality of the mobile phone (ii) delivery and acceptability of health information via mobile phones (iii) use of mobile phones in the	User acceptance study – are mobile phones as a tool acceptable for receiving health information and supporting healthcare in this rural context? Would the mobile phone be an adaptable tool for supporting healthcare delivery in an LMIC?	Participants did not consider receiving health information to their phones an intrusion to their personal life. They preferred voice communication to all other forms of communication. Factors such as sex, English literacy, employment status and presence of chronic disease affected preferences regarding mode and content of communication. The	India (rural) Chronic Feasibility study: 558 households	99% of respondents felt mobile phone used to deliver healthcare interventions is acceptable. 89% of respondents preferred voice communication to SMS reminders. 79% thought receiving reminders for drug adherence was acceptable.

management of chronic illnesses (iv) use of mobile phones in the management of acute illnesses and (v) acceptability of usage of cell phones for health promotion. Questionnaire based study looking into the acceptability of mobile phones as a tool for management of chronic illness, as well as usage patterns.

preference for voice calls among older respondents indicates a probable discomfort in operating mobile phones to access an SMS or a difficulty with reading SMSs. For the management of chronic illness, 98% preferred to receive medication adherence reminders via SMS. The majority of those questioned were willing to receive health-related information via their mobile phones, and did not consider it to be intrusive.

Nhavoto et al. (2015)
SMSaude: Design, Development,

SMS appointment reminders, medication reminders, motivation and educational messages to facilitate communication

Improve/promote patient's self-management skills and strengthen communication

Support self-management from the clinician. This study demonstrated that it is possible to design, develop, and implement

Mozambique
HIV and TB

Improved patient retention to HIV/AIDS when SMS were sent as appointment, medication, motivation and educational reminders to patients enrolled in antiretroviral therapy.

*and
Implementation
of a
remote/Mobile
Patient
Management
System to
Improve
Retention of
Care for
HIV/AIDS and
Tuberculosis*

between patients and healthcare system to aid the management of HIV and TB. Processes of design, development and implementation of a remote management system using mobile technologies to help patients with HIV and TB to improve self-management of their treatment.

between patients and healthcare providers. To design, develop and implement an integrated mobile phone SMS system that can be used to follow up with patients undergoing HIV and TB treatment in Mozambique.

an integrated remote patient management system using the mobile phone's text-message feature to communicate with patients.

Non-RCT:
Patients enrolled in ART and TB treatment programmes aged 18 and over and basic Portuguese. 750 patients over 5 sites selected according to: 1) currently in first line of antiretroviral treatment, 2) aged 18 years or older, 3) have basic literacy skills in Portuguese, 4) own a cell phone, and 5) not be part of other on-going research.

Piette et al. (2012a) <i>Hypertension Management Using Mobile Technology and Home Blood Pressure Monitoring: Results of a Randomised Trail in Two Low/Middle-Income Countries</i>	Randomised trial on the effect of home BP monitoring and automated behaviour change/ monitoring phone calls on systolic BP in hypertensive patients. Use of mobile phone and additional home monitoring kit. Patients received. Recorded information in Spanish during interactive voice calls about diabetes management. Patients were reminded to check their BP regularly/ask about recent systolic values, medication adherence and intake of salty foods. Patients' receives additional self-care info and prompts to seek medical attention to address high or low BP.	Behaviour change telephone calls to provide self-management education and information to patients. Enable the patient to take blood pressure measurement at home instead of travelling to a health facility-to give blood pressure data to clinician-receive feedback form clinician to adjust treatment - how to best self-monitor or improve self-management e.g. salt reduction/exercise. Hypertension is a growing problem in	Primary outcome: improved systolic blood pressure using Home blood pressure monitor Secondary outcome: Perceived health status and medication related problems. HbA 1c levels improved from an average of 10.0% at baseline to 8.9% at follow-up. Patients reported that the intervention caused them to take medication more regularly and carefully, change diet and discuss their hypertension with their doctor more regularly. Patients considered the intervention easy to use, useful for helping them manage their hypertension and that it was a satisfying experience	Honduras and Mexico (Rural and semi-rural) Hypertension RCT: 200 Men and women with Hypertension (18-80 years) (100 Honduras, 100 Mexico). All patients between 18 and 80 years of age and had access to a cell phone or landline telephone and had an SBP over 130 mm Hg if diabetic or over 140 mm Hg if non-diabetic.	The intervention led to improvements in patients' depressive symptoms, medication related problems, perceived general health, and treatment satisfaction. Among patients with low literacy or significant needs for hypertension-related communication, the intervention led to a clinically significant improvement in systolic BP. Intervention patients had an average systolic BP 4.2mmHg lower than the control group. In the subgroup with low literacy, this average increased to 8.8mmHg. A cloud computing approach to automated telephone self-management support, coupled with home BP monitoring may improve BP control in LMICs.
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Email alerts for health-workers generated automatically when patients reported measurements needed attention or if they never reported. Patients could enrol family/friends to receive an automated update about the patient's self-reported health status weekly and how they can self-manage more effectively.

LMIC. Can automated telephone interventions improve outcomes in an LMIC setting?

overall.

<p>Piette <i>et al.</i> (2014) <i>Establishing an independent mobile health program for chronic disease self-</i></p>	<p>Automated telephone monitoring (interactive voice response) and self-management support. In addition to weekly IVR calls as described below, patients with hypertension received a home blood</p>	<p>Weekly interactive voice calls to mobile or landline phone. Patients reported info about their perceived health status, changes in their</p>	<p>Home blood pressure monitor. Despite infrastructure challenges, an mHealth intervention in Bolivia is feasible, as discovered on result of the cross sectional survey.</p>	<p>Bolivia Diabetes and Hypertension Feasibility Pilot: 176 Men and women with</p>	<p>NCD patients in LMICs reported reliable information during IVR monitoring and self-care support calls. There is some evidence that such calls can improve their health status. Patients generated clinical alerts during more than half of the weeks in which they completed an</p>
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*management
support in
Bolivia*

pressure monitor and were trained in its use, including how to keep a daily record of their systolic blood pressure values. All participants received 12 weekly IVR calls to their mobile or landline telephones, with multiple call attempts at times the patient indicated were convenient.

Sample n=20 were interviewed about patient satisfaction of the programme and if it helped their chronic disease self-management. Development of a telephone based intervention through questionnaire to ascertain phone access and use. Testing of mHealth

health, medication adherence and amount left, check if they were regularly checking their blood pressure and whether they were avoiding salty foods. They were then given tailored self-management. Clinic physician was point of contact acting on email notifications generated automatically bases on patients IVR health and self-care reports. Cross sectional survey: Is an mHealth intervention feasible in the

Patients were willing to engage with the IVR trial.

Diabetes and/or Hypertension 1144 participants in initial survey on demographics and access to mobile phones 664 in secondary survey chosen on chronic health conditions. Data presented from subset of 364 patients who participated in both surveys and had diabetes or hypertension. 165 in IVR trial.

IVR call. High rates of alerts may reflect pent-up need for care associated with barriers to accessing NCD treatment and self-management support. 82% of those questioned in the survey had a mobile phone. Overall IVR completion rate was 51% and the majority of patients were satisfied with the trial.

interactive voice response (IVR) calls intervention for patients with diabetes or hypertension in an LMIC.

target population to improve outcomes in non-communicable diseases.

Pop-Eleches et al. (2011)
Mobile phone technologies improve adherence to antiretroviral treatment in a resource-limited setting: a randomised controlled trial of text-message reminders

Automated SMS reminder for medication adherence for those initiating ART and/ or additional support receiving short or long mobile phone text-messages, either daily or weekly. Participants were provided with the basic phone. RCT to test the efficacy of SMS on adherence to ART in HIV/AIDS patients in an LMIC.

Receive short or long reminder SMS sent daily or weekly. Does adoption of an SMS reminder service increase adherence to ART in an LMIC, and does the frequency of the messages affect this.

Medication event monitoring

The primary outcome was ART adherence of <90% during each 12-week period of analysis, for 48 weeks. Weekly SMS reminders increased the proportion of patients adhering to ART versus the control group as well as the proportion of patients not having treatment interruptions of >48 hours.

Kenya (resource-limited)

HIV
 RCT: 431 Men and women diagnosed with HIV who had initiated ART within 3 months.

Participants receiving the reminder SMS were significantly less likely to experience treatment interruptions exceeding 48hours. Adding words of encouragement was no more effective than shorter direct messages. Weekly reminders improved adherence but daily reminders did not. 53% of participants receiving weekly SMS reminders achieved adherence of at least. Longer SMS reminders were not more effective than either a short reminder or no reminder. These weekly reminders were also effective at reducing the frequency of treatment interruptions, which have been shown to be an important cause

of treatment resistant failure in resource-limited settings. Adherence at 90% for patients receiving the intervention was 75.8 over the 48-week trial period. Adherence in eh control group was 60% in weeks 1 – 12 and 46% in weeks 37–48. The adherence was significantly higher than control in the group receiving weekly reminders. The adherence was not significantly higher than the control group for those receiving daily SMS reminders.

Rotheram-Borus <i>et al.</i> (2012) <i>Diabetes Buddies Peer Support Through a Mobile Phone Buddy System</i>	Psycho-educational support intervention: Education/ Persuasion/ Enablement Uptake of text-messaging, body mass index, blood pressure, styles of coping, emotional distress, sedentary time	Peer/social support for behaviour change via SMS – text-messaging and phone calls to a buddy to support lifestyle changes. Psycho-educational support small groups (self-help)	The purpose of this study is to test the feasibility and acceptability of a mobile phone–based peer support intervention among women in resource-poor settings to self-manage their diabetes. Secondary goals were to evaluate the	South Africa Diabetes Pilot (12 week, single arm intervention): 22 Women aged 21-74 diagnosed with diabetes.	Both positive and negative changes were observed in this pilot study. Positive effects on sleep, positive action, and coping. More text-messages between buddies than to the programme (19883 vs.1321). 29% response rate to text questions. Higher diastolic blood pressure (+7 mmHg) and less spiritual hope at six months. ‘High-texters’ had higher
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A series of educational group sessions addressing lifestyle improvements were offered to diabetic women and each was assigned a 'text-message buddy' to assist with lifestyle changes via SMS.

meetings in person with nurses content included health cooking/physical activity/medical management of diabetes.

Disseminate health messages. Healthy lifestyle behaviour reminders sent via SMS daily to remind women to monitor their walking and eating behaviours.

Women must respond via SMS to the research team.

intervention's effectiveness to motivate diabetes- related health choices.
Check number of messages exchanged.

BMI's and more sedentary time.

Lester *et al.* (2010)
Effects of mobile phone short message

SMS support reminder to improve adherence to ART medication.
Forwarding weekly SMSs to Non-intervention

Receive weekly SMS from clinic nurse to enquire about their status and to remind them

Primary outcomes were self-reported ART adherence (>95% of prescribed doses in the past 30 days at both 6-

Kenya

HIV

RCT: 273 Patients

Adherence to antiretroviral treatment reported in 168 of 273 patients receiving the SMS intervention compared with 132 of 265 in the control group. Suppressed viral loads

<i>service on antiretroviral treatment adherence in Kenya (WelTel Kenya 1): a randomised trial</i>	participants to share support. SMS support service-Support Adherence to ART drug regime via SMS – patient could phone anytime during clinic hours. RCT to assess the effect of mobile communication with healthcare workers on treatment adherence and treatment outcomes in a group of chronically ill patients based in a low resource setting.	about the availability of phone-based support. Patients must respond within 48hrs that they were doing well or had a problem. The clinician phoned if they had a problem or failed to respond in 2 days. Regular structured mobile phone communication between health-workers/patients. Reminder to patients to take ART. Does the use of mobile phone communication between HIV/AIDS patients/healthcare	and 12-month follow-up visits) and plasma HIV-1 viral RNA load suppression (<400 copies per mL) at 12 months. Adherence to antiretroviral therapy was significantly increased in the intervention group versus controls. Plasma viral load suppression was significantly reduced in the intervention group versus controls. Mobile SMS can improve treatment outcomes.	initiating ART treatment Received intervention 265 (total: 538) Received standard care HIV-infected adults over 18 years initiating ART for the first time.	reported in 156 of 273 patients in the SMS group and 128 of 265 in the control group. Both adherence to ART and suppression of viral load was improved in the intervention group vs. the control group.
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workers in an LMIC improve treatment adherence and suppression of viral load?

Mbuagbaw et al. (2012b) <i>The Cameroon Mobile Phone SMS (CAMPS) Trail: A Randomised Trial of text Messaging versus Usual Care for Adherence to Antiretroviral Therapy</i>	Motivational SMS to improve adherence to ART medication. Receive weekly-standardised motivational SMS - patients did not have to reply. Support helpline offered (phone call not SMS). Could call back if help was needed. RCT to assess the effect of a weekly motivational SMS on treatment adherence in management of a chronic condition in an LMIC.	Reminder SMS to take medication – cue to action and opening up communication channels. Content varies. Messages developed using the health belief model of behaviour change. Are standardised SMS messages an effective means of improving treatment	The primary outcome was adherence measured using a visual analogue scale (VAS), number of doses missed (in the week preceding the interview) and pharmacy refill data. The use of motivational weekly messages did not increase adherence to medication use in the intervention group above the level of the control group.	Cameroon HIV: 101 HIV 21 years and above on ART (for at least one month) Intervention Control: 99 (total 200)	No significant effect on adherence. At six months overall retention was 81.5%. Text messaging was viewed positively as a tool with a dual function of reminder and motivator. Messages coming from the attending physician may have a stronger impact. <i>(*The trial protocol (2011) and the qualitative study (2012) were also referred to).</i> There was no significant increase in adherence on any of the outcome criteria of the intervention group versus the control group.
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adherence to ART
in an LMIC
setting?

Mbuagbaw <i>et al.</i> (2012a) Considerations in using text-messages to improve adherence to highly active antiretroviral therapy: qualitative study among clients in Yaoundé, Cameroon	Qualitative study using focus groups to assess their views on the use of mobile SMS motivational messages as a reminder to adhere to a medication regimen as management of a chronic condition.	What are the views of HIV patients on ART about the use of mobile SMS messages as a reminder to comply with their treatment regimen? What are their motivating factors to comply, and how could this influence SMS content? Data will be used to design a clinical trial.	Participants' recognised treatment adherence was difficult and would appreciate some form of reminder. Half believed a SMS would be useful, and highlighted that this would be more valuable if sent from a physician. There was no consensus on content or timing.	Cameroon Chronic Qualitative – 32 participants, data analysed for 30	Participants recognised treatment adherence was difficult and would appreciate some form of reminder. Half believed a SMS would be useful, and highlighted that this would be more valuable if sent from a physician. There was no consensus on content or timing.
Hoffman <i>et al.</i> (2010). <i>Mobile Direct Observation Treatment for</i>	Treatment supporters (family/friends) took phone videos of TB patient swallowing their medication daily and sent	Patient is videoed taking the medication. Health professional reviews video	To ensure patient has taken TB treatment daily and questionnaire to rate comfort with technology, receptivity to different	Kenya TB	MDOT is technically feasible. All participants preferred mobile direct observed treatment over clinic direct observed treatment or visiting health-workers. Both patients and health

<p><i>Tuberculosis Patients: A technical Feasibility Pilot Using Mobile Phones in Nairobi, Kenya (MDOT)</i></p>	<p>video via MMS to health professional. Patients receive 1 MMS video (testimonials from other patients/advice from physicians and TB prevention messages) and 4 SMS health messages per week motivational and educational TB SMS. Video-capable mobile telephones were provided to patients. Feasibility study: proof of concept pilot using questionnaires to ascertain the viability of mobile direct observation of treatment (MDOT) along with motivational SMS and mobile media for treatment adherence in a chronic condition.</p>	<p>empowering both the patient and health professional by the ability to communicate with each other. Is MDOT a technically feasible option in the management of TB in Kenya? Is this a preferred management option for patients?</p>	<p>types of health messages, and preference for MDOT over other DOT options. MDOT is technically feasible.</p>	<p>Feasibility pilot: 13 Patients and their treatment supporters.</p>	<p>professionals appear empowered by the ability to communicate with each other and appear receptive to remote. MDOT and health messaging over mobile.</p> <p>Survey comments from both patients and nurses indicated that access to each other for timely, ad hoc communications was empowering for both groups.</p> <p>Patients also indicated they now felt someone cared for them and they felt more optimism for being cured.</p> <p>Nurse receptivity was high. They noted that MDOT provides a mechanism for providing a higher level of care and timely, proactive intervention to address real-time needs, such as medication side effects or counselling against compliance default. MDOT is a technically feasible method of monitoring patient adherence to TB medication. Patients were satisfied with MDOT as a management tool.</p>
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Leon et al. (2015b) <i>Improving adherence for blood pressure lowering via mobile phone SMS-messages in South Africa: a qualitative evaluation of the SMS-text Adherence Support (StAR) trial</i>	<p>Study to determine if prompts via SMS-text-messaging improve adherence to clinic visits and treatment? Find out more about impact and patient perceptions of support interventions in low-resource settings. Provide practical and emotional support for improving adherence behaviour. Interviews and focus groups as part of qualitative evaluation.</p>	<p>To explore trial (unpublished results) participants' experiences and responses to the SMS and identify barriers and facilitators to delivering adherence support via patients' own mobile phones.</p>	<p>Patient comfort with the technology Acceptability and relevance of SMS Effects of intervention on attitudinal and behaviour change. Changes in acknowledgment of disease status and attitude.</p>	<p>South Africa Hypertension 22 participants who took part in the StAR trial</p>	<p>Messages were experienced as acceptable, relevant and useful to a broad range of participants (36-78 years). SMS content was respectable in tone and the delivery (timing of reminders and frequency) and the relational aspect (feeling cared for) were all highly valued. Subgroup who benefited most had been struggling with adherence due to high levels of personal stress. Behaviour change may have been facilitated through increased acknowledgment of their health status and attitudinal change towards greater self-responsibility. Many already had their own reminder system in place.</p>
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Results from the studies suggest that mobile phones are an acceptable modality for receiving health information, with a preference over voice to text reminders (DeSouza *et al.*, 2014). Motivational and educational messages can aid the patient's skills to self-manage HIV by actively digitally monitoring (Nhavoto *et al.*, 2015; Mbuagbaw *et al.*, 2012b). Patients who used home monitoring kits to report health information about their perceived health status and changes in their health and medication adherence had improved blood pressure control (Piette *et al.*, 2014; Piette *et al.*, 2012a). Several studies relied on automated text reminders for medication adherence, particularly for those initiating ART (Mbuagbaw *et al.*, 2012b; Lester *et al.*, 2010; Pop-Eleches *et al.*, 2011). Weekly reminders improved monitoring and adherence, but daily reminders did not (Pop-Eleches *et al.*, 2011). It was found that adding words of encouragement was no more effective than shorter, direct messages (Pop-Eleches *et al.*, 2011:825). In urban South Africa, the provision of practical and emotional support for improving adherence behaviour via text was found to be useful in addition to a patient's existing reminder system such as family support (Leon *et al.*, 2015b). Two studies reported the use of a proxy to act as a text-message buddy. This had positive effects on a diabetic patient's amount of sleep time, positive actions and coping strategies (Rotheram-Borus *et al.*, 2012). Another study used family and friends as treatment supporters to video the TB patient swallowing their medication. Videos were sent via multimedia messaging service to the health provider,

who would reply via text-message by providing practical and emotional support for improving adherence behaviour (Hoffman *et al.*, 2010). The sample was too small to decide if the intervention worked sufficiently and there were issues with sending the video.

The CMOc for each empirical study was then determined (Appendix 2). Table 10 demonstrates a worked example of a CMOc from one of the empirical studies included in this review. The example given is from the Rotheram-Borus *et al.* (2012) diabetes buddy study in South Africa.

Table 10. Example CMOc determined from the diabetes mHealth study by Rotheram-Borus *et al.* (2012)

Context		Mechanism	Patient action (Reasoning)	Outcome
Patients routinely taking medication	Diabetes buddies to offer peer support	Different SMS probes sent daily about adhering to a healthy lifestyle	Patient reads message probe, understands content and monitors their eating and walking	Patient blood glucose level improves through behaviour change. Does not change behaviour related to diabetes significantly. Positive effect on sleep.
Patient education about self-care for diabetes is minimal	Diabetes buddies to offer peer support	Different SMS probes sent daily about adhering to a healthy lifestyle	Patient does not read content probe and/or Patient does not monitor their	Patient feels accountable to someone.

			eating and walking	
Patient education about self-care for diabetes is minimal	Diabetes buddies to offer peer support	Patient can reply to SMS	Patient replies to SMS	Patient feels empowered and that someone cares and greater optimism for them so adopts change in behaviour. Women responded only 54% of the time. Positive effect on coping.
Patient education about self-care for diabetes is minimal	Diabetes buddies to offer peer support	Patient can reply to SMS	Patient does not reply to SMS	No change in behaviour.
Patient education about self-care for diabetes is minimal	Diabetes buddies to offer peer support	Information sent by trained buddies, via SMS to patient about lifestyle change	Patient responds via SMS or voice to buddy for extra support	Increased quality and frequency of peer support. On average 123 texts exchanged between patient and buddy per week.

To visualise the combined and refined CMOC from the empirical studies, Figure 12 was created. It describes an example of monitoring intervention for chronic diseases in LMICs to summarise the resource/reasoning. This was adapted from Dalkin's *et al.* (2015:4) Context–Mechanisms–Outcome model.

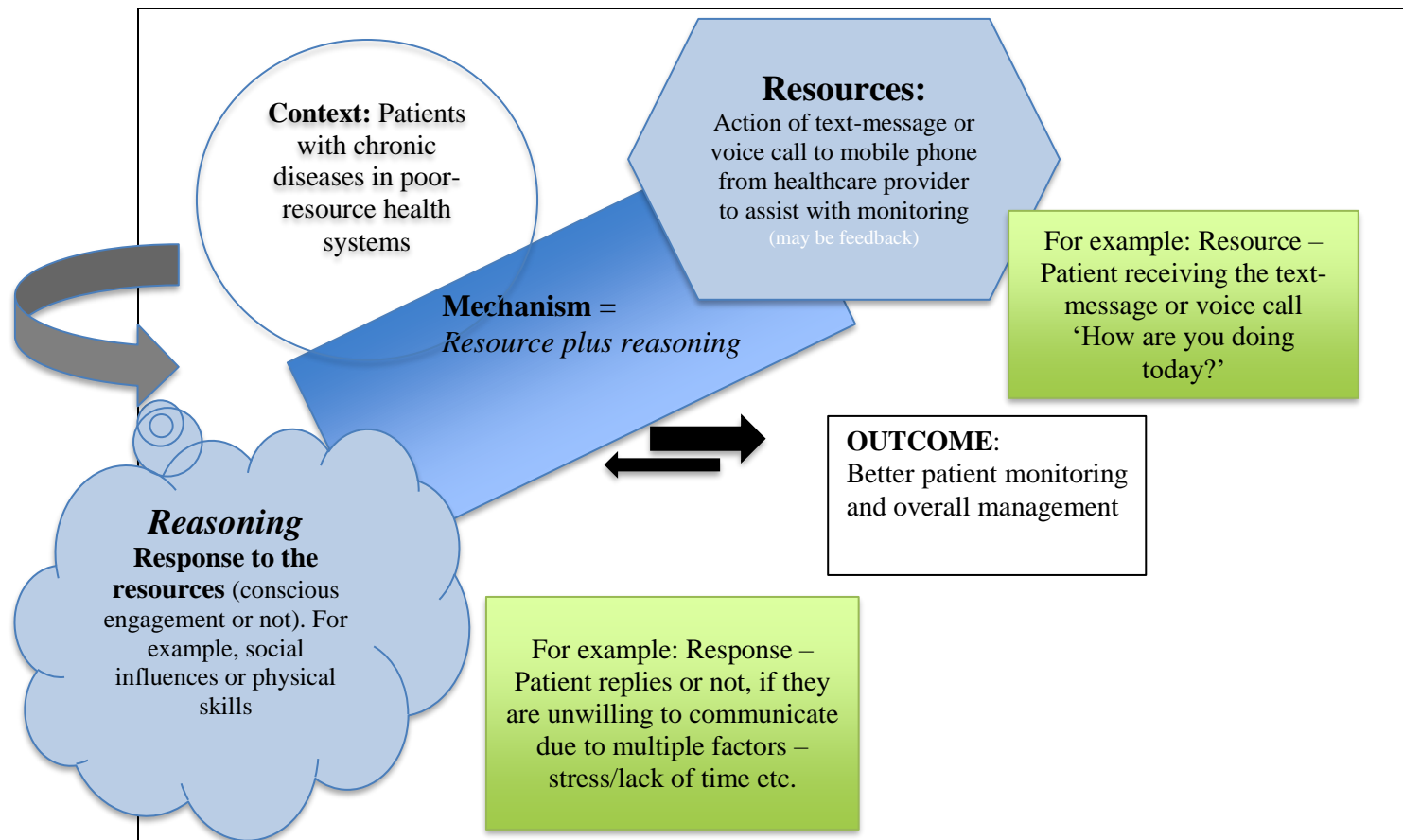


Figure 12. Refined Context–Mechanisms–Outcome configuration (CMOc) for patients with chronic disease in LMICs receiving/sending mHealth interventions by text or voice (layout adapted from Dalkin et al. (2015:4))

For example, a patient with a chronic disease in a poor-resource health context receives the resource of a text-message, ‘How are you today?’, sent to their phone from the healthcare provider to assist with mobile monitoring. The second resource is the patient’s phone. A response is triggered once the patient’s own reasoning as a reaction to the resource is fired. This may be a conscious engagement or not. For example, the social influence could be a friend already managing their disease through mobile monitoring. The response could be a reply to the health-worker, who might reply with advice. If so, the intended outcome – improved monitoring through dual management – might result. A visual of this description of a hypothetical example of community health-workers in Malawi is shown in Figure 13, influenced by Campbell’s *et al.* (2014:3) pathway.

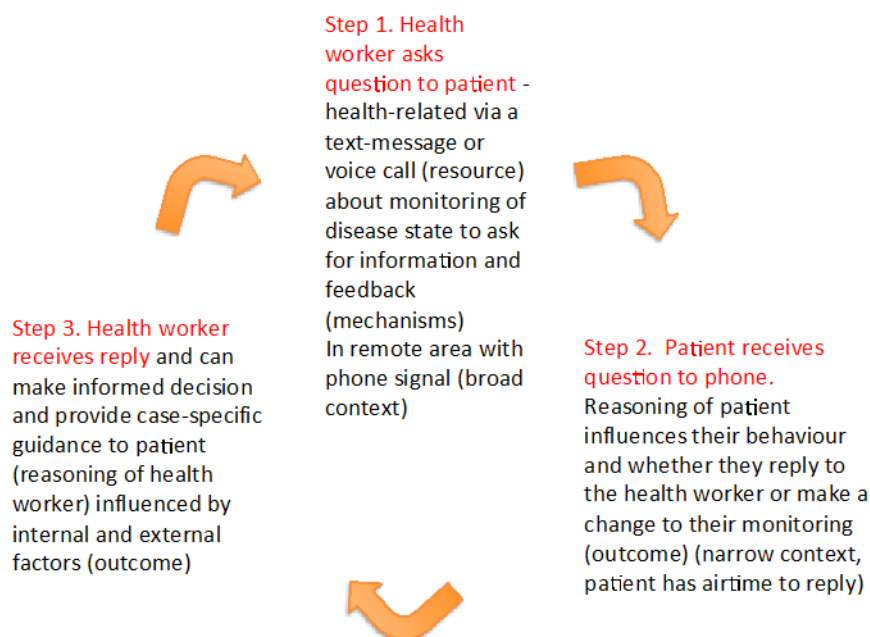


Figure 13. Diagram to illustrate an example CMO pathway from the health-worker to the patient

By describing the typical CMO pathway, Figure 13, assisted in developing the proposed programme theory. The study authors were not explicit about how they intended their interventions to work. However, the common mechanisms identified from the empirical studies were as follows (Box 5).

Proposed programme theory:

If a patient with a chronic disease can use text/voice (*mHealth resource*) to help monitor their condition using two-way mobile communication (communicating digitally via a mobile phone) to/from a health professional (interaction between patient and provider), then access to healthcare, which is meaningful/valued/effective (process outcome) potentially improves clinical and behavioural outcomes.

The exchange of clinical or behavioural information communication of vital changes/states and the ability to receive remote support and feedback is increased through these digital communication channels.

This improves or increases or enhances better chronic disease management because more consistent, structured, reliable, efficient, timely, educated monitoring occurs.

Box 5. Proposed programme theory from empirical studies in this review

Overall, the studies have indicated that, if patients are given the opportunity to monitor using a phone or specialised mobile devices, the channels of communication between the patient and health provider are increased. In turn, this encourages the patient to comply with their treatment regimen because a health-worker is in contact with them either via one- or two-way mobile communication. These mechanisms in the proposed programme theory are now discussed in relation to relevant high-level theory.

Section 2: High-level theory and CMO refined theory

From the combined CMOc, the nine mechanisms that mobile monitoring interventions should include (depending on the aim of the monitoring) with the related theory are introduced in Table 11.

Table 11. Theory and mechanisms from empirical studies (resource and response to intervention) – patient capacity to monitor chronic disease using mobile health communication

Domain and High-level theory	Type of mechanism (resource)	Empirical studies (response/reasoning)	Domain, Theory and Example
Goal setting Goal Setting theory	Decision-support	Nurse finds defaulters and plans restarting patient on treatment (Hoffman <i>et al.</i> , 2010)	Domain of Goal setting under Goal Setting theory (Locke & Latham, 1994) related to the mechanisms of Decision-support suggests that working towards a determinate rather than abstract goal (Miner, 2015). The process of goal setting mediates the difficulty of the task (taking medication or observing a mood state). Digital mobile decision-support is likely to aid the accomplishment of goals.
Increased communication channels and access Health communication theory Access Framework	Support line (enables the possibility for relationships with health professionals)	Patient can receive counselling and info about symptoms/side effects (Hoffman <i>et al.</i> , 2010). Buddy offers support to assist with lifestyle changes (Rotheram-Borus <i>et al.</i> , 2012). SMS sent as reminder about phone-based support (Lester <i>et al.</i> , 2010) SMS sent as reminder about phone-based support (Mbuagbaw <i>et al.</i> , 2012b)	Domain of Increases communication channels and access under Health communication theory (Northouse & Northouse, 1992) and Access Framework related to the mechanisms of Support line suggest that using mHealth enhances transactions (Berry, 2006) and access to support from a clinician. For example, if the patient can receive digital counselling in the form of tailored self-managing given as feedback after submitting monitoring readings.

		<p>Tailored self-management is given as feedback after the voice call (Piette <i>et al.</i>, 2014)</p> <p>Longer SMS gives patient additional support/encouragement (Pop-Eleches <i>et al.</i>, 2011).</p>	
<p>Accountability/ Expectation/ Role models Communication for persuasion</p>	<p>Observation (visual/ Adjustment monitoring)</p>	<p>Patient is observed taking medication in person (Hoffman <i>et al.</i>, 2010)</p> <p>Clinical officer to enquire indirectly about patient's HIV status with 'how are you?' (Lester <i>et al.</i>, 2010)</p> <p>A patient listens to interactive voice response call and reports their perceived health status including changes in their health (Piette <i>et al.</i>, 2014).</p>	<p>Domain of Accountability/ Expectation/ Role models under Communication for persuasion related to the mechanisms of Observation suggest that a patient can be persuaded by a role model whom they feel accountable to and there is an exception that being observed and then reporting this back to someone who is waiting on the information makes the patient feel they need to do as expected/persuaded (Petty & Cacioppo, 2012), which makes them feel more persuade to keep up with their monitoring.</p>
<p>Self-empowerment Social Influences Information-Motivation-Strategy model (IMS-B)</p>	<p>Motivation</p>	<p>A buddy can act as a motivator (Rotheram-Borus <i>et al.</i>, 2012)</p> <p>Motive statement '<i>Remember you are important to your families</i>' (Mbuagbaw <i>et al.</i>, 2012a).</p>	<p>Domain of Self-empowerment and Social Influences under Information-Motivation-Strategy model (IMS-B) related to the mechanisms of Motivation suggest that adherence to a treatment recommendation or making a health-behaviour change requires patients to have (a) Information (i.e. know what health behaviour they should change or treatment they should under go and the purpose) (b) Motivation (i.e. have the desire to carry out the behaviour change or adherence to treatment motivated any their beliefs, expectations and feelings); and (c) Strategies to make the behaviour change or adhere to treatment (i.e. have the mental, monetary and social resources</p>

			<p>including social support necessary to adhere to change their behaviour (Martin <i>et al.</i>, 2011).</p> <p>Incentive to behave (health motivation) e.g. receiving motivational messages can increase a person's likelihood of committing to monitoring because they are being influenced by the message and possible change their monitoring behaviour as a result.</p>
<p>Social Influences</p> <p>Social learning theory/ Social cognitive theory</p>	<p>Reinforcement and feedback</p>	<p>Patient watches video of recovered patient (Hoffman <i>et al.</i>, 2010).</p>	<p>Domain of Social Influences under Social learning theory (Bandura, 1977) or Social cognitive theory related to the mechanisms of Reinforcement and feedback.</p> <p>Value of health status – behaviour is regulated by its consequences (reinforcements) but only as those consequences are interpreted and understood by the individual.</p> <p>By watching a mobile video of a recovered patient, this may reinforce patient's feelings of determination to want to improve. Consequently digital feedback can act an influencing factor in making changes.</p>
<p>Behavioural regulation/ Optimism</p> <p>Self-regulation theory</p>	<p>Health promotion</p>	<p>To adopt health lifestyle and monitor healthy eating and exercise (Rotheram-Borus <i>et al.</i>, 2012).</p>	<p>Domain of Behavioural regulation and Optimism under Self-regulation and Self-Perception Theory (Bem, 1973) related to the mechanisms of Health promotion suggest that attitude change resulted from a simple inference based on observation of one's own behaviour. If a patient observes their behaviour, which is part of their monitoring of their mood.</p> <p>If a patient receives a call or message about adopting a healthy lifestyle this promotes a behavioural change</p>

			Davey <i>et al.</i> (2015) postulates that monitoring and feedback can be understood within control theory: a model of self-regulation.
Knowledge Health Belief Model	Information	Patient reads prevention messages for TB (Hoffman <i>et al.</i> , 2010). Patient listens to automated call for information about what monitoring needs to be done (Piette <i>et al.</i> , 2012a).	Domain of Knowledge under Health Belief Model (HBM) (Rosenstock, 1974) related to the mechanisms of Information . Explain and predict preventive behaviour. HBM hypothesises the patient needs sufficient motivation (or health concern) to make health issues salient or relevant; the belief that one is vulnerable to a serious health problem as a perceived threat; and the belief that following a particular recommendation would be beneficial in reducing the perceived threat. Increasing patient knowledge through mobile information reminder or learning messages.
Cue to action Theory of planned behaviour	Reminders	Reminder subtly reminds patients to take their ART (prompts patient into thinking about how they are that day. Patient must reply to nurse within 48hr about how they are / Patient likely to take medication (Lester <i>et al.</i> , 2010). Direct reminder to take medication 'please remember to take our medication' (Mbuagbaw <i>et al.</i> , 2012b). Reminder prompts response, to communicate with healthcare-provider (Nhavoto <i>et al.</i> , 2015). Patient reads blood pressure results-out (Piette <i>et al.</i> , 2012a).	Domain of Cue to action under Theory of planned behaviour (Ajzen, 1991) related to the mechanisms of Reminders . Reasoned action model - we are aware of the thoughts and feelings that lead up to our decisions (attitude toward behaviour). Reminder messages to attend clinic appointments to improve retention to care or for taking medication to increase adherence can act as a cue to action to stimulate the patient into action. The behaviour can then normalised over time. Normalisation theory can play role in the macro mechanisms but this can not be tested as it is not falsifiable.

		Direct reminder to take medication (Pop-Eleches <i>et al.</i> , 2011).	
Skills Cognitive load theory	Education/ Advice	Patient listens to advice by physicians (Hoffman <i>et al.</i> , 2010). Teaches patient self-management skills on how to self-monitor (Nhavoto <i>et al.</i> , 2015).	Domain of Skills under Cognitive load theory related to the mechanisms of Education/Advice . To predict learning outcomes by taking into consideration the capabilities and limitations of the human cognitive architecture (Plass <i>et al.</i> , 2010). Accounts for the demands that a certain task imposes on an individual but does not consider the psychological effects that individual's beliefs, expectations and goals have on their load perceptions. If a patient listens to advice given by a health professional via text or voice, the educational advice, it is possible that if the patient is capable of understanding what they have read or heard changes can be made.

An example from this table suggests that the ‘support line’ mechanism relates to the theory of ‘access’. The mechanisms presented along side theory are now discussed in relation to theoretical domains and concepts in Table 12 and Table 13.

Table 12. COM-B domains: capability, opportunity, motivation for mobile monitoring interventions based on findings from the 11 empirical studies

COM-B Domains for effective mobile monitoring	COM-B summary results: relevant to monitoring using text and voice for these domains as suggested from empirical studies
1. a) Physical Capability <i>(Physical skills)</i>	Patients need the physical skills to use and access the mHealth intervention on their phone. The ability to understand how to text and receive calls (appropriation of technology).
1. b) Psychological Capability <i>(Knowledge, behavioural regulation and memory, attention and decision processes)</i>	Patients need to know about and be able to use, and understand and respond to the SMS or voice call and to self-manage symptoms with some health professional interaction. They need to know the red flags and monitor their symptoms to determine when seeing a health professional is necessary to adjust treatment for example. These decisions are based both on experience and newly acquired management skill, where the phone acts as a support tool to enhance/aid these skills.
2. a) Physical Opportunity <i>(Environmental context and resources)</i>	The environment should be set-up to make it easy for the patient to navigate and know and understand how and when to make changes. Monitoring will help this. Patients make use of the given resources (phone ownership/accessible use of a phone, context, to interact with other domains such as psychology capability = the reasoning element).
2. b) Social Opportunity <i>(Social influences)</i>	Patients can observe others monitoring their long-term disease. Healthcare professionals and peers should reinforce these behaviours. There may need to be a shift in cultural norms about how to manage

	a long-term condition because they are newly diagnosed, already have a disease. The health professional will expect a certain level of self-management from the patient. Other patients are actively using their phones for monitoring, peer influence learning.
3. a) Reflective Motivation <i>(Beliefs about consequences, optimism and beliefs about capabilities)</i>	Patients will need a level of self-motivation in order to successfully manage and monitor their disease. They need to succeed at doing this over time so that they experience good outcomes in terms of symptom severity and duration. The patients' actions (monitoring) and the health professionals' actions (supporting and feedback to the patient) need to be seen as visibly contributing to the effective healthcare of the patient. Mobile health communication can contribute to assisting in motivation by reinforcing what monitoring needs to be achieved in that hour, on that day.
3. b) Automatic Motivation <i>(Reinforcement and emotion)</i>	Patients' decision making is influenced by emotion and the need for reassurance from a medical professional and thus feedback to the patient is important for monitoring.

The layout of this table is adapted from Public Health England (Pinder, 2015:49) using Michie's et al. (2013:4) COM-B domains; the content is a combined example from the empirical studies.

These COM-B domains suggest that, in order for an mHealth monitoring intervention to be effective, the patient must engage with all three domains. These encompass many of the mechanisms found in the empirical studies. For example, the patient needs a level of reflective motivation in order to successfully manage and monitor their disease. The physical capability of the patient to comprehend the mechanisms of education and advice are necessary. Reinforcement from peer/social influence suggests that support from a

treatment supporter or health professional will aid the monitoring process. A patient can use the resources of the mHealth intervention to achieve the ends that are important to successfully monitoring their condition. However, a young TB patient who is in the early stages of initiating TB chemotherapy may respond better to a new mHealth monitoring intervention than an older, hypertensive patient with stable blood pressure who has been on medication for a long time.

Table 13 describes how Vassilev's *et al.* (2015) concepts of relationship, fit and visibility in relation to Michie's *et al.* (2013) domains of capability, opportunity and motivation are related to mechanisms, as resources from the empirical studies.

Table 13. Review summary of the high-level theoretical concepts, domains and theories related to monitoring mechanisms from the 11 empirical studies

Concept (Vassilev <i>et al.</i> , 2015:1)	Type of related Domain (Michie <i>et al.</i> , 2013) and High-level theory from literature <i>as</i> <i>supporting evidence to</i> <i>mechanism</i>	Type of mechanism - resource (<i>from the empirical studies</i>)	Capability, Opportunity and Motivation domains (<i>are agency dependent and aid triggering of response</i>)
Relationship	Increases communication channels and access Health communication theory Access Framework	Support line (enables the possibility for relationships with health professionals)	Capability Opportunity Motivation

	Accountability role models Communication for persuasion Social influences Social learning theory/ Social cognitive theory Cue to action Theory of planned behaviour	Observation (visual/ Adjustment monitoring) Reinforcement and feedback Reminders	
Fit	Skills Cognitive load theory	Education/Advice	Capability Opportunity Motivation
Visibility	Goal setting Goal Setting theory Self-empowerment Information-Motivation-Strategy model Behavioural regulation and optimism Self-regulation theory Knowledge Health belief model	Decision-support Motivation Health promotion Information	Capability Opportunity Motivation

Table 13, indicates that the concept of *relationships* relates to increased communication channels and access, accountability role models, social influences and cues to action. This supports the mHealth monitoring mechanisms of support line, observation, reinforcement, feedback and reminders. The concept of *fit* relates to skills and supports the mHealth

monitoring mechanisms of education and advice. This supports the mHealth monitoring mechanisms of education and advice. The concept of *visibility* relates to behavioural domains of goal setting, self-empowerment, behavioural regulation and optimism, knowledge and cues to action. This supports the mHealth monitoring mechanisms of decision support, motivation, health promotion and information. The three domains of *capability, opportunity and motivation* are agency-dependent and aid the triggering of response as a reaction to the intended mechanisms and the intended behaviour that results. Depending on the relationships, fit and visibility of the given intervention resources and the resources of the patient and their individual capability, opportunity and motivation, the intended mechanisms will trigger the desired outcomes in the given context. If a patient is exposed to the mechanism of support line and given feedback after the voice call, as the intervention involves a tailored self-management system (Piette *et al.*, 2014), then Health Communication Theory (Northouse & Northouse, 1992) suggest that the communication between the patient and health provider improves the patient's health. This is because the messages are innovative, relatable and motivating (Edgar & Volkman, 2012). The patient can appropriately adjust their treatment and therefore improve health gain.

3.5 Realist review novel theoretical framework

The results tables and figures from sections 1 and 2, are illustrated in a framework (Figure 14) to visually present the findings and increase their use when applied to future designs of mHealth monitoring interventions.

Population: Chronic disease where outcome is improved by monitoring and adjustment of treatment (medication or behaviour)

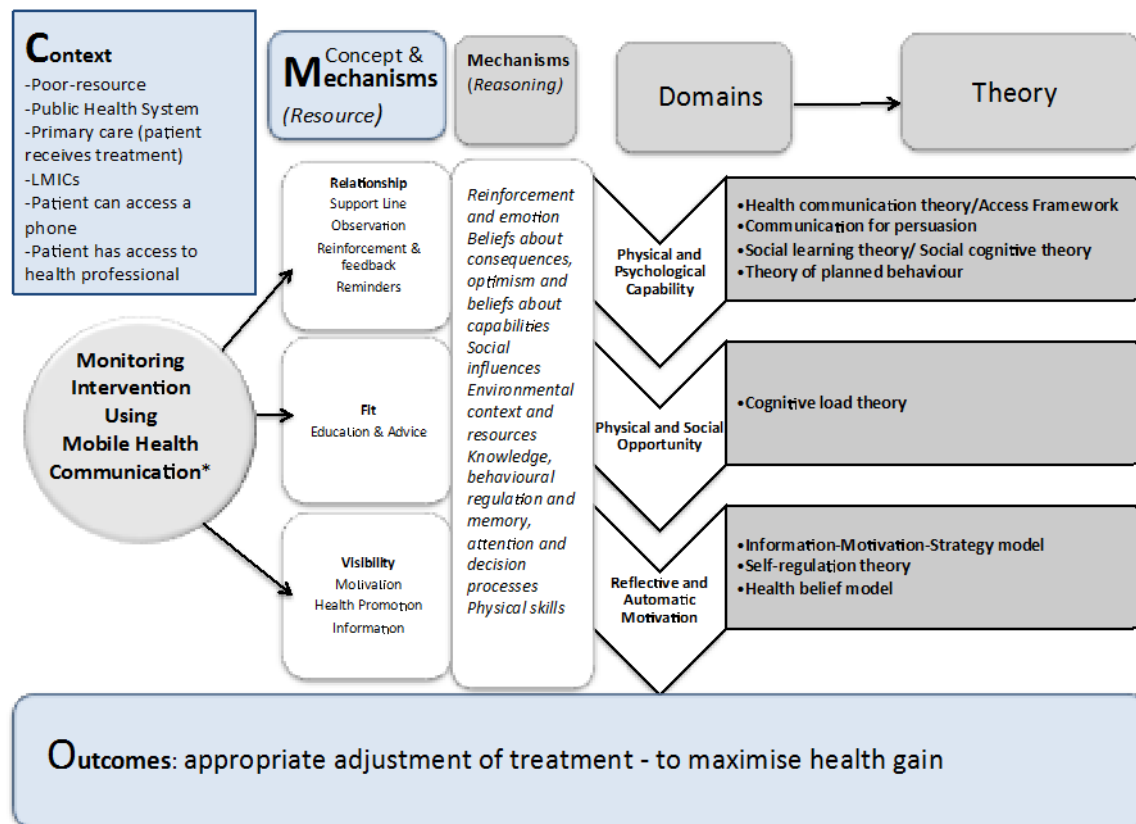


Figure 14. Novel theoretical-conceptual realist framework for mHealth interventions for the monitoring of chronic diseases in LMICs, informed by high-level theory, domains and concepts

The framework (Figure 14) illustrates:

- The **population**: patients monitoring chronic disease to improve outcomes (or possibly adjusting medication or behaviour).
- The **context**: poor-resourced primary health care, public health system in LMICs, where a patient have access to a mobile phone and to a health professional (for example, a nurse or doctor).
- The resource **mechanisms** from the **mHealth monitoring intervention** are divided under the **concepts** of relationships, fit and visibility.
- The reasoning **mechanisms** are listed next to the **domains**, which are related to **theory**. It could be argued that these mechanisms are necessary for monitoring to be effective.
- The CMOc produces the final **outcome**, being the appropriate adjustment of treatment to maximise health gain.
- **Refined programme theory**: it is important to take into consideration one or more of the proposed mechanisms when designing an mHealth monitoring intervention for patients with chronic diseases in LMICs. If one or more resource mechanisms from the intervention is present along with reasoning mechanisms from the individual and domains of capability, opportunity and motivation, intervention outcome (maximising health gain) is likely to result.

3.6 Review discussion

This realist review set out to understand whether digital monitoring interventions are likely to work and, if so, for whom and in what context. With better theoretically derived designs, there is the likelihood of more effective interventions for patients with chronic disease in low-resource settings.

Little attention has been given to monitoring using digital technology for chronic patients in LMICs, but, mechanistically and through a theorised synthesis, it is possible that mHealth interventions are likely to result in the desired outcome of maximising health gain. Largely, mHealth monitoring interventions are not robustly developed with often limited theoretical frameworks supporting them. This review has therefore tackled the components of monitoring studies determining the CMOc from each study, to propose overall mechanisms necessary for successful mobile monitoring. These should be applicable to any chronic disease, since there are only a certain number of mechanisms available for any intervention, though this needs testing. The results demonstrate that mHealth monitoring should work for patients with chronic diseases, if implementers account for one or more resource and reasoning mechanisms in line with theory from the outset.

The results of this review suggest that a combination of mechanisms is desirable for the target outcome to result. Most empirical studies targeted one or more mechanisms. If there are one or more mechanisms used in the design of the intervention, this may enable a reaction or response by the patient to make a desired change. If more than one mechanism is presented, then there is a greater chance that the patient's reasoning will react to the available resources. For example, the mechanism of motivation would be more effective if this were also presented with a reinforcement and feedback mechanism. If the patient is motivated by setting goals for monitoring their disease, then this could be accompanied by a role model or peer supporter to act as a social influence to either reinforce behaviour or give relevant feedback.

A strength of this review is that mechanisms have been drawn from each empirical study and combined with already-known theoretical constructs to build a framework. This should potentially move the mHealth chronic disease monitoring agenda forward by building on the gap in knowledge of how mHealth interventions work or do not work. The mechanisms in the novel framework will be used to contribute to understanding and finding the CMO configurations from the Vutivi primary results. It will guide the interpretation of findings and the development of a more consolidated theory from these initial hypotheses.

This review has several limitations. The literature retrieved in Review b related predominately to more highly researched chronic diseases such as HIV and TB. These diseases have historically been investigated in health domain silos rather than collectively. This is largely because of the nature of how research is funded in medical investigations. It is unknown whether findings can be representative of other chronic diseases but it is very probable since the mechanisms for each disease are unlikely to be significantly different.

A realist review is not reproducible in the same sense as a Cochrane review. Therefore quality assurance was considered, but this is more dependent on explicitness and reflexivity on the part of the reviewer. An audit trail was documented during the entire iterative process and an independent quality checker was used for data extraction. Only a small number of realist reviews have been completed, compared to the gold standard Cochrane reviews, as this logic of enquiry is still in its infancy. Even when undertaken well, a realist review promises no certitude in terms of findings or recommendations. Findings can often be tentative and ‘fallible’ (Pawson *et al.*, 2004:38).

There are practical constraints on the depth and breadth of this review. Primarily, this review has been undertaken as part of a PhD. Time and human resources were limited compared to a review team working on a fully funded

review. Pawson *et al.* (2004) caution that completely comprehensive reviews are impossible. Parameters were therefore set and these boundaries were discussed with the supervisors.

The academic community and other implementers of mHealth interventions concerned with monitoring can use this framework to better understand why their digital applications may work, and for whom, when and where. It may be useful in designing and thinking through the mechanisms by which the mHealth interventions focus on. Mechanisms need to be well thought through so that valuable resources and time are not wasted as chronic disease prevalence continues to increase.

Implications for policy and practice are acknowledged. The review has aided the understanding of what mechanisms could be at play depending on the monitoring aim of the study, and therefore how the mHealth monitoring intervention may be working, given the contexts and resources. However, what is still not clear is whether the interventions are effective over long durations, or for chronic diseases that were not included in the empirical studies, such as mental health conditions or asthma, and, lastly, whether the desired outcome will result if a patient has comorbidity.

The novel framework could feed into the development of future robust mHealth monitoring interventions in LMICs for patients with chronic diseases and inform possible scale-up. More research into the effectiveness of mHealth monitoring interventions for particular stages of a disease, or for patients who have comorbidities is warranted. The mHealth monitoring intervention may be more advantageous for certain patients depending on their chronic disease, stage of illness, gender and age.

Any mHealth component must support or complement the process of care delivery, rather than be a substitute. Future research could also include sending messages to caregivers who may act as treatment supporters or moderators to the patient. Leon *et al.* (2015b:8) suggest that ‘the focus on a single behavioural or cognitive target for adherence interventions’, such as motivation, might account for the failure of many interventions to bring about sustained behaviour change. Therefore, considering one or more mechanisms is advocated. However, response mechanisms are agency-dependent and this must be considered in the design phase. Not all intended mechanisms would result in the desired outcome if the patient’s reasoning does not align with their own resources or those offered by the intervention. Future research should determine the efficacy of using a home monitoring kit in addition to using a mobile phone.

Also the unintended consequences of monitoring disease digitally should be taken into account in future research. For example, clinical staff in South Africa do not necessarily have the capacity to sufficiently respond to a patient. Currently, nurses are responsible for patient monitoring activities such as checking vital signs. Therefore, in addition to this, a policy change could be monitoring patients at home using their mobile phones. This would need to be a robust mobile monitoring system whereby adequate resources for both the patient and the health-worker are provided (though not everyone may be willing). This system includes an incentive for patients to self-monitor and the ability of nurses to respond in a timely manner. A willingness to adopt, adapt and accept digital technology, as part of chronic diseases management must be combined with buy-in at the primary care level and staff engagement in low-resource health systems.

3.7 Chapter 3 review conclusion

Monitoring is a complex part of the management of a chronic disease and requires significant effort and regular attention by the patient. Glasziou *et al.* (2005:644) explain that, when it comes to monitoring, ‘poor choices can lead to poor control, poor use of time and dangerous adjustments to treatment’. Therefore, two-way digital monitoring in addition to face-to-face monitoring increases the channels to support chronic disease management over time.

‘Shared-care management’ of chronic disease (Wildevuur & Simonse, 2015:1) can be enhanced through digital interactions.

Finally, using the proposed framework and the effective design considerations from the review of reviews, mobile interventions for monitoring patients with chronic diseases could be effective in primary care in low-resource contexts. The results from this review will inform the interpretations of the primary results of the Vutivi study (Chapter 6) by testing whether the mechanisms are transferable to other contexts.

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To follow, Chapter 4 describes the methods for the Vutivi study.

Chapter 4



Photo 7. Mama Matlala sitting with family members outside

Chapter 4: Methodology and methods of the Vutivi study

4.1 Overview of Chapter 4

This methods chapter addresses the following sections:

- a) The broad methodological approach
- b) Study setting
- c) Methods procedures (Phases 1-8)
- d) Fieldwork, ethics and challenges
- e) Methodological strengths and limitations
- f) Analysis strategies
- g) Research dissemination

4.2 a) The broad methodological approach

Overview of the Vutivi study research design of primary data collection

Figure 15 illustrates the methods used in data collection (Stage 2 of the research design).

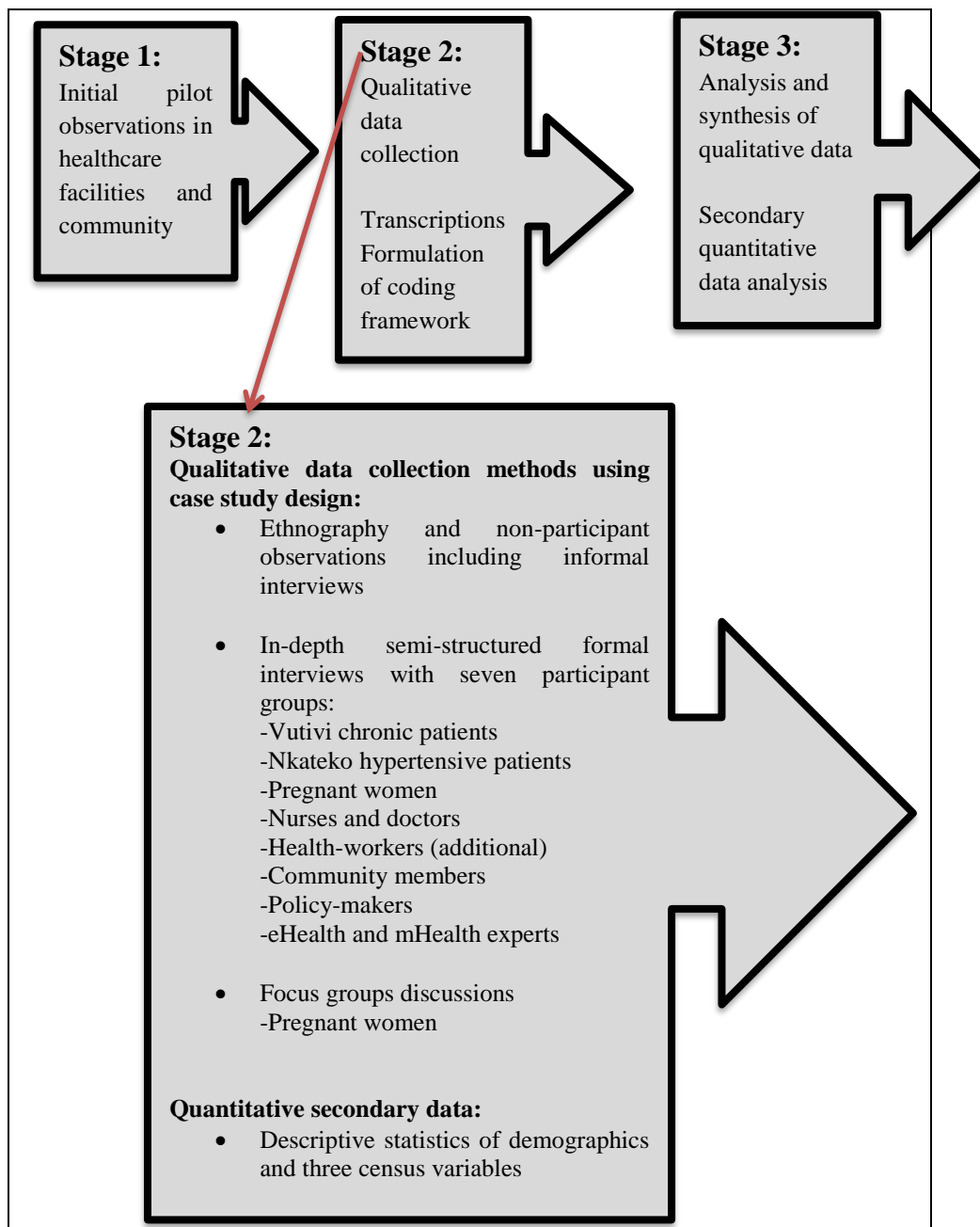


Figure 15. Research design summarising the methods and design used in Stage 2 of data collection

This is a complex exploratory study consisting of a multi-methods approach, using case study design. To address the research aim and objectives,

qualitative methods integrated in-depth interviews, focus group discussions and a prolonged engagement in non-participant observations in clinics and within the community as indicated in Stage 2 of the research design (Figure 15). The choice of qualitative methodology was crucial in allowing the research to focus on participant's experiences (Colaizzi, 1978) to understand more about a new phenomenon (Tesch, 2013). Data was triangulated during thematic and comparative analysis (Gilson *et al.*, 2011; Denzin, 1970).

In addition, a secondary quantitative data analysis of the Agincourt HDSS census data, aided the contextualisation and interpretation of the qualitative findings by describing descriptive statistics of relevant variables.

Analysis of primary qualitative and secondary quantitative data, synthesis of theory and policy discussion was then integrated into the overall findings. The theoretical-conceptual framework (Figure 2) guided the development of the research design.

To address Research Questions 2-4, data was collected from n=231 multiple key informants from distinct participant groups: patients with chronic diseases (Vutivi and Nkateko), pregnant women, nurses and doctors, additional health-workers, policy-makers and eHealth and mHealth experts. Interviews were undertaken to explore the experience of healthcare, meanings, dynamics, current and potential uses of technologies within in the

clinics and local community. Each data collection phase informed the next phase and so on.

Epistemological commitments

The epistemological ‘positionality’ taken is that of realism. This was discussed in Chapters 1 and 3. Emmel (2013:157) suggests that ‘social reality is not simply captured by descriptions of events and experiences; it is far richer and deeper within a social system’. The realist researcher must always seek to explain ‘what works, for whom, in what circumstances and why’ (Pawson & Tilley, 1997). The qualitative methods used in this study aim to address this realist question by working out the relationship between ideas and evidence, between insiders’ perspectives and experiences of events and outsiders’ understandings of the causal mechanisms that bring about change (Emmel, 2013:6).

Case study design

The study uses case study design (Yin, 2013). South Africa as the single case study and embedded within that, a case study on the Agincourt HDSS. Case study research is in line with realist principles. Realists are concerned with understanding how each case contributes to the interpretation and explanation and how ideas are tested and refined within cases and between cases (Swanborn, 2010). Cases provide ‘bounded units in a potentially limitless

open social system’ with the purpose of describing what is going on in a particular setting (Emmel, 2013:107). Yin (2013:141) suggests that cases can make a significant contribution to ‘theory building’ and knowledge. This research provides a representative case, capturing circumstances (patients and health-workers in rural health facilities using eHealth and mHealth), likely to be typical of other rural settings.

The case study design was used to allow an in-depth investigation of the interrelated factors underlying the participant’s experiences (Neuman & Kreuger, 2003). The shortcomings of the case approach include the researcher’s own subjective bias, difficulty of replication, and non-representative and time-consuming cases (Hammersley & Atkinson, 2007). These have been recognised as issues that could arise in any qualitative design.

Description of methods used in the empirical data collection

Justification of multiple data collection methods

The choice of multiple methods is appropriate since focus group discussions, in-depth interviews and ethnographic observations enable the investigation of attitudes, meanings, experiences and behaviours from many participant’s perspectives. Creditability of the findings was enhanced through iterative data collection. Interviews and observations occurred on the same day enabling an overall representation of the research environment. Gilson (2012) endorsed

that to ensure rigour in qualitative data collection, prolonged engagement with the subject of enquiry is paramount. Data was collected over a continuous twelve-month period (September 2013-2014).

Ethnography and observations in the community and healthcare facilities

A pivotal mode of ethnography was non-participant observation and interviews. The ethnographer's gaze demands two things: 'being able to locate the mundane features of extraordinary situations and to identify what is remarkable in everyday life' (Silverman, 2007:23). Ethnography allows for the observation of ordinary practices that cannot always be detected in interviews. The strength of ethnography is the potential for rigorous and authentic stories from the perspective of local people (Fetterman, 2010). In ethnography, the primary 'research instrument' is the researcher (Hammersley & Atkinson, 2007:19). It is therefore crucial that researchers locate themselves within the research environment and try to explicitly reflect on how personal subjectivities affect research and research relationships, such as the researcher's ethnicity, language and appearance. 'Researchers bring prejudices, prejudgements, theories, frames of references and concepts to their choices' (Emmel, 2013:158).

Waldman and Stevens (2015:3) explain that it is not unusual in qualitative research to speak to high-level actors engaged in policy formation or

implementation and be able ‘to reflect on their challenges’. In this study, we aimed to get both emic (from the perspective of the observer, for example the policy-makers) and etic (from the perspective of the subject, for example the patients) responses. Petersen *et al.* (2005:1237) describe this process as ‘the participant’s view of what is happening, with the researcher interpreting the emic data from their etic perspective which the researcher brings to bear on the data’.

Informal interviews

Informal interviews or ‘natural conversations’ (Green & Thorogood, 2013) occurred spontaneously and fortuitously in the field. This data was gathered opportunistically and played an important role in developing an overall account of people’s perceptions to healthcare topics and technology use. These conversations provided the ‘backbone’ to the formal interviews.

Formal interviews

Formal interviews with each participant group were selected on the grounds that they provided unique and different information. Interviews increased the understanding of social phenomena (Bowling, 2014:144). All interviews were semi-structured and guided by an interview schedule.

There are a number of actors, each playing a role at the micro-, meso- and macro-levels within the health system. Interviews were undertaken with ‘actors’ at each level. Each actor’s perspectives about their role within the healthcare system and where eHealth and mHealth can fit were discussed to generate data on beliefs and behaviours (Green & Thorogood, 2013).

Focus group discussions

The purpose of conducting focus group discussions (FGDs) with pregnant women, in addition to interviews was to elicit ideas in a group environment. Bowling (2014:410) suggests that FGDs ‘create a space to stimulate discussion, gain insights and generate ideas in order to pursue topics in greater depths’. A period of time lapsed between the interviews and FGDs allowing for discussion around topics that had arisen in the interviews where more detailed explanations were needed.

Data saturation

Data saturation was interpreted when new ideas relating to the study aim ceased to emerge from the data (Creswell & Clark, 2007). The term saturation point (Glaser & Strauss, 1967) or data sufficiency (Suri, 2011) is in line with realist methodology that seeks to test theories until data saturation (Wong *et al.*, 2010). In the Vutivi study, sampling for interviews continued until a

diversity of participants who were demographically different within each group.

Documentary analysis

A documentary analysis of policies, strategies, parliamentary speeches and clinical guidelines publically available from the NDOH's website, were also analysed. Sampling of documents was based on relevancy to eHealth and mHealth and those mentioned by interview participants. These documents have been discussed as contextual background in Chapter 2 and to follow in Chapter 7.

Preparation and familiarisation

Access into the study site was only made possible due to the long-standing engagement between Warwick and Wits and the established and venerable engagement that the Agincourt Research Unit has with the community: Shangaan chiefs, known as the Indunas, community leaders and members and the healthcare facilities. The Learning, Information Dissemination and Networking with the Community (LINC) team facilitated access into the field site. This was useful because often researchers enter as 'strangers' (Hammersley & Traianou, 2012:54).

It was a concern that interviewing within study site clinics could be hampered by the participants' 'general fatigue' from the research process (Clark, 2008:953). This was overcome, as the research topic was relevant to everyone, as generally mobile phones are peoples' prized possession. There was no direct incentive to take part other than good will and perhaps intrigue.

Mixed-methods research design

A 'dominant-less-dominant' design of QUAL/quant was used, also known as 'an exploratory design' (Ivankova *et al.*, 2006:3). This sequential design gives priority to the qualitative over the quantitative method. It was important to make use of 'the richness of differing methodological traditions' by integrating them (Kelle & Erzberger, 2004:158). This was appropriate for this study's complex research questions (Dixon-Woods *et al.*, 2004).

The rationale to use a mixed-method approach was made in the attempt to counteract the biases that are associated with mono-method studies (Gilson, 2012). Green and Thorogood (2013) propose that researchers should 'appeal to the deficit model' of traditional clinical and epidemiological research, as qualitative methods 'reach the parts other methods cannot reach'. There is also the opportunity for complementarity of results. The secondary quantitative data analysis allowed for expansion of the findings by adding richness, detail and potentially, validation of the qualitative findings.

4.3 b) Study setting

Research location

Geography and demographics

The MRC/Wits Rural Public Health and Health Transitions Research Unit runs the Agincourt Health and Demographic Surveillance System (HDSS) study site. The HDSS is in the rural sub-district of Bushbuckridge, in Mpumalanga province in northeast South Africa. Mpumalanga is adjacent to Mozambique. The study site borders with the Kruger National Park (Figure 16).

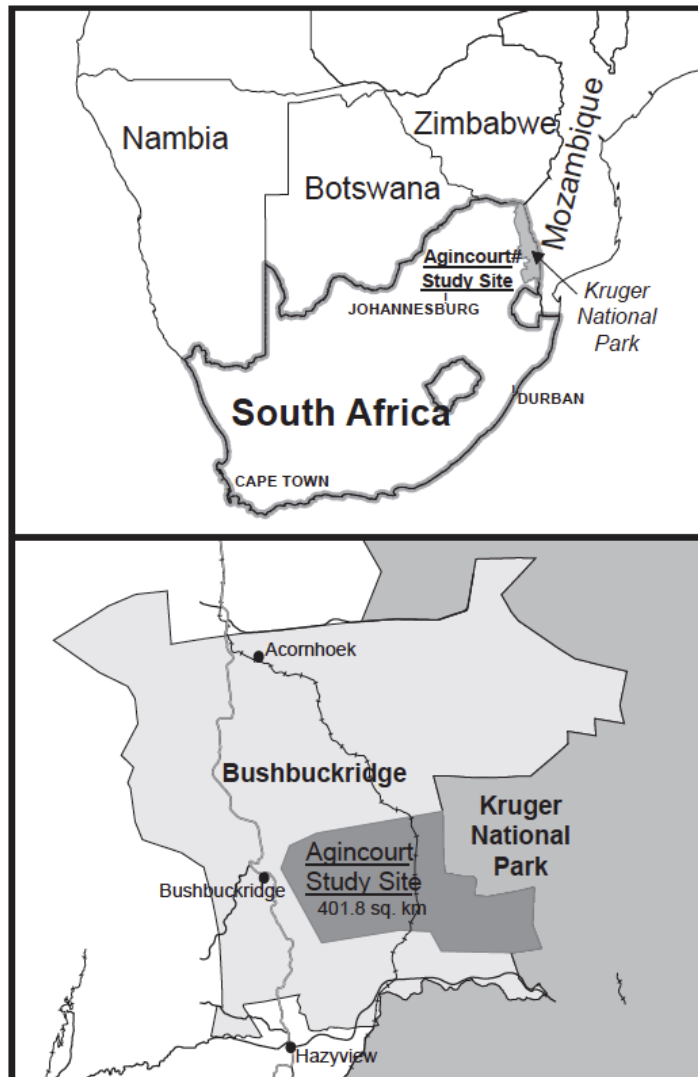


Figure 16. Map of the Agincourt HDSS field site, Mpumalanga, South Africa (*Sartorius, 2013:29*)

The HDSS monitors the population in a clearly defined geographic area. The study site covers 420km², encompassing 32 villages with 16,000 households (*Kahn et al., 2012b*). Annual census data has been collected at the site since 1992 at 12-month intervals from approximately 107,500 people (52,592

people are older than 18 years) and one third are Mozambican immigrants (Kahn *et al.*, 2012b:989).

Demographic surveillance is undertaken annually to generate research questions and hypotheses from empirical data. It also highlights health, social and population priorities, and provides cost-effective support for diverse study designs and tracks population change and the impact of interventions over time' (Clark *et al.*, 2007:956). The HDSS held a baseline census in 1992 and annual updates have been conducted of household memberships and individual status variables (Kahn *et al.*, 2012a). There is also enquiry into vital events such as pregnancy outcome, death, and in- and out-migration (Fottrell *et al.*, 2011). Each individual and household has a unique identity number (Thorogood *et al.*, 2007; Mayosi *et al.*, 2009). Community members receive the results of the annual census every winter via community engagement days held in each village. The Community Advisory Group (CAG) has representatives from each village, who review and advise on all research. Black African Shangaan people speak the indigenous language locally known as Xitsonga or Xishangaan and are part of the Tsonga ethnic group.

The study site area has historically experienced forced in-migration of families, high levels of economic out-migration for labour to cities

(traditionally miners and domestic workers who send remittances home), food scarcity and limited access to land for food production. The area is typical of rural communities across South Africa characterised by poverty, high human densities, few employment opportunities, relative social isolation and reliance on natural resources (Kahn *et al.*, 2012b).

The rate of HIV in the Agincourt population above 15 years old is 24 per cent in women and 11 per cent in men (Gómez-Olivé *et al.*, 2013). Mpumalanga has the highest first test positive rate for pregnant woman in South Africa (Day *et al.*, 2011).



Photo 8. The rural study site location: the journey to the clinics in the rainy season (January, 2014)

Although the study site is rural due to its remoteness from a main service hub, the description of rurality is being challenged because households are not necessarily dependent on agriculture and are densely settled, remote and under-served. Many families collect firewood for cooking. Despite the government's development initiatives, which have led to improved housing, access to water pumps and social security, infrastructure is still limited and high unemployment rates. In the last few years, electricity has become available in most villages. The municipality is in the process of tarring several major dirt roads in the study site.

Mobile phone penetration in the study site is around 93 per cent per household. This is up from 35 per cent in 2005 (Agincourt, 2014a). There is potential for appropriate technological innovation to support health service design. Although the locality is poorly served in terms of infrastructure (transport and broadband Internet) the situation is rapidly improving with phone masts for 3G signal.



Photo 9. Typical housing in the study site: a mix of traditional huts and new dwellings with corrugated iron roofs

Health services within the rural HDSS

The health facilities provide comprehensive primary healthcare services to the community who are largely socio-economically deprived. The facilities are often within walking distances of the people's homes, or they can travel by public transport (bus or minibus).

Within the field site there is a complex health system with eight clinics and two health centres indicated on the map with red crosses (Figure 17). The district hospitals are on the periphery. The primary health clinics range in size from small 'satellite' clinics with only one nurse to larger clinics served by

ten or more nurses. The nurse to patient ratio is approximately one nurse, per one hundred patients, per day.

Agincourt Sub-District and Study Site

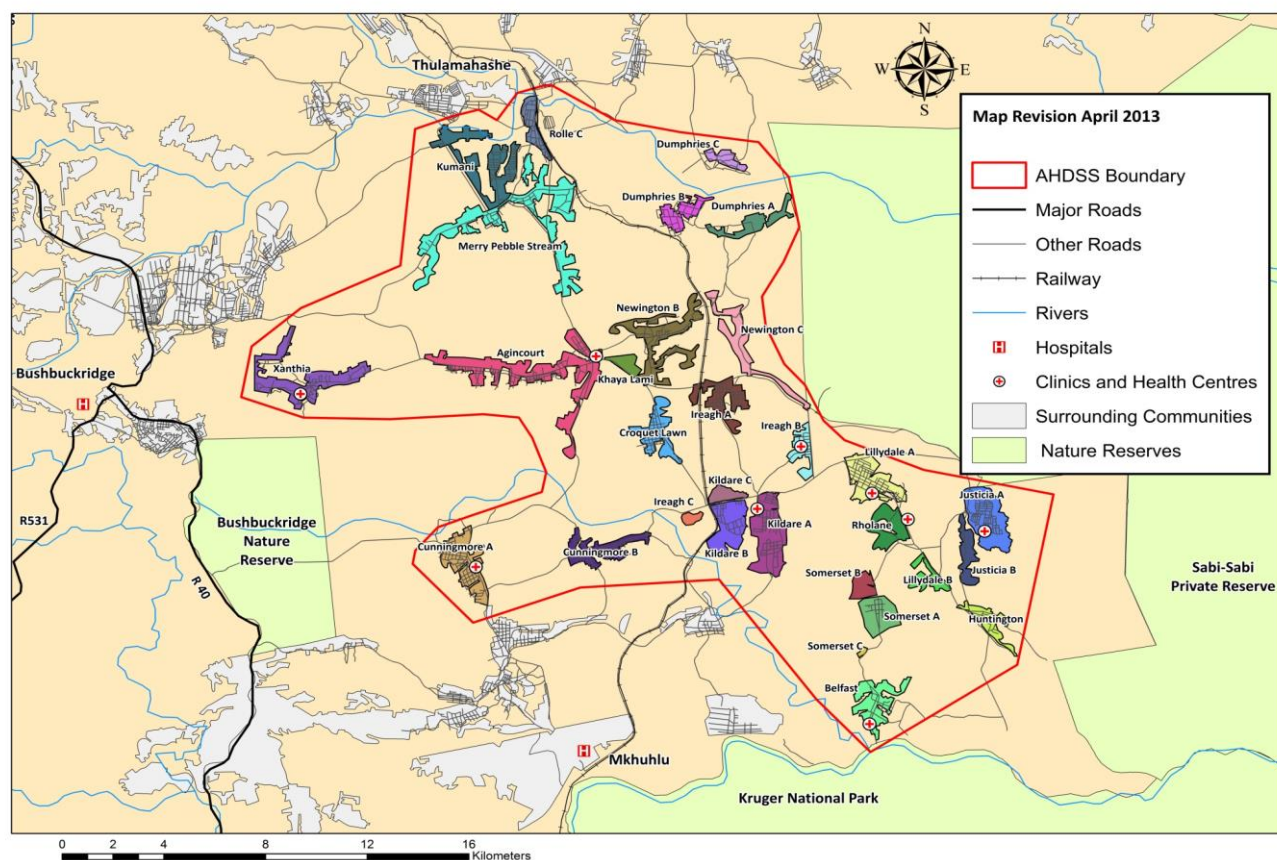


Figure 17. Map of Agincourt Sub-District and Study Site (Agincourt, 2014b)

Provision of primary care in the study site

For chronic disease services, a nurse reviews stable patients receiving treatment every three to six months. At clinical review, patients are prescribed medication on repeat until their next scheduled appointment. The nurses from the onsite pharmacy dispense medicines in 28-day increments. It is unusual to have a clinic pharmacist in the rural areas (Leon *et al.*, 2015b). All patients must have their vital signs checked by a nurse when they arrive at the clinic.

Pregnant women attending for antenatal care should be seen by the nurses at the clinic four times during their pregnancy. The maternal care guidelines states that basic antenatal care involves the identification of risk factors and early diagnosis of pregnancy complications and appropriate management and health education (NDOH, 2015a:15).

4.4 c) Qualitative methods procedures: Phases 1-8

The next section describes the qualitative data collection methods procedures for each participant group. Each group differed in terms of preparation, research time, location, and interview questions. Field implementation strategies including sampling, recruitment and data collection procedures are described separately for each participant group unless the same process was followed.

Phase 1: Formative phase - fieldwork preparation and data entry

Familiarisation with the field site

During the first three months, visits to local health facilities and shadowing of field site research staff was conducted. This formative period was essential in understanding the context and local culture. Therefore observations, informal conversation and field notes began from the onset.

Experience of clinics within the study site

During the preliminary stages, introductory and scoping visits to several primary health clinics were conducted. The main objective of these visits was to obtain an overall understanding of how the clinics operated on a daily basis. Time was spent with a Wits researcher and clinician, understanding the Integrated Chronic Disease Management model through his ‘Vunene study’. This research was very relevant to the Vutivi study to inform my understanding of rural chronic disease care and the general organisation of the primary care environment.

Experience of villages within the study site

To ensure that the research was within the ‘Fieldworker and Researcher Guidelines’ (Agincourt, 2016), I accompanied several fieldworkers familiar with the healthcare facilities and clinic staff. Time was spent with them working on the 2013 census in two villages, at community members’ homes. The example extract in Table 14, describes the experiences of the home visits.

<p>House 1. One tall paw-paw tree, a cluster of banana trees, neatly brushed, amazing view, high up, family home. The fieldworker called out ‘Hello, anyone at home?’ in Xitsonga. A</p>

lady came out of the brick house, with a tin roof and brought three plastic chairs. We greeted each other. The lady was the eldest child and she would respond on everyone's behalf. The form had to be dated next to the dwelling number and village number.

House 4. *We sat on the stoop, whilst the gogo (Grandmother) sat on a handmade mat cracking her peanuts. She said the rains were coming soon so she was preparing the peanuts to be planted. She also had an extensive vegetable patch. I asked the fieldworker – if the men are not working away as migrants – what employment do they find in and around the study site – she said either teachers, work for the municipality or they are just on the booze (alcohol). This was the first house where I noticed that when the fieldworker requested a cell phone number and the respondent did not know it off by heart – the respondent would hand the cell phone over to the fieldworker to go through the phone book and check the numbers on the census form.*

Table 14. Extract from field notes during preparation for fieldwork (October, 2013)

Two further days were spent with the 'Verbal Autopsy Fieldworkers' who collect cause of death data from the deceased's family (Byass *et al.*, 2010:2). Time was also spent with the Nkateko fieldworkers as part of the preparation for the cluster-randomised trial. The Nkateko research team was conducting a questionnaire and collecting clinical measurements related to high blood pressure at community members' homes in a further two villages.

Overall, the experience within the villages was fundamental to gain an understanding of how and where people live, village locations and the general running of the census and other research projects.

Experiences within the district hospital

After this formative period in the field, preparations began for the mini pilot conducted at the district hospital. Permission was granted in writing from the acting hospital CEO. This opportunity allowed for the nurse and patient interview schedules to be piloted and adjusted accordingly. Informal discussions and general non-participant observations took place over one-week situated at the reception desk, with the data clerk manning the phone and computer and in the consultation room. This pilot allowed me to gain an understanding about the provision of antenatal care.

Preparation to conduct research in health facilities and sampling of clinics

The LINC team translated participant information sheets, posters and consent forms from English to Xitsonga.

As is usual in case study research, four clinics were purposively sampled (Patton, 2005) to include two clinics within the study site and two clinics on the periphery (Figure 17). The decision to choose two clinics outside of the study site was to ensure a sample of patients and nurses who had no prior experience of Wits research. This also alleviated the research load from the study site clinics, which had been subjected to many projects over the years.

Description of the clinics recruited

Within the study site: one small old clinic accessible via a newly built tar road and one newly built clinic only accessible via dirt roads, both in small study site villages.

Outside the study site: one health centre (larger clinic with overnight beds) in a large village and one small clinic in a small village.

A brief presentation was given to the nurses at each clinic and a date agreed for the interviews to commence. We requested to spend four days in each clinic from 7am-4pm (clinic opening hours). The nurses were provided with a research folder, including a study summary and poster in both English and Xitsonga, for staff and patients to read (Appendix 3).

Description of patients recruited

The patient groups were from the general adult population attending outpatient chronic disease services and/or antenatal care.

Ethnography and non-participant observation in primary healthcare facilities

Obtaining informed consent for general clinic observations

Before conducting non-participant observation and interviews, consent was requested from the clinic nurse. The fieldworker informed all other staff about the study and its purpose at a staff meeting.

Ethnographic process in the community and within clinics

Non-participant observation of the general environment, waiting rooms and clinic consultation rooms was conducted to understand the research environment. Clinics were observed at different times and days over a few months, in such a way to not disrupt the everyday running of the clinics.

Formally these observations were non-participatory, recorded as field notes and structured through ‘an observation checklist framework tool’ (Appendix 4). This tool drew attention to physical space, patient flow and interaction among patients and

providers. Less formally, we were often drawn into the daily routine such as drinking tea with the nurses in the staff kitchen, singing and dancing during the morning prayers and chatting to patients in the queue who were intrigued of my presence and the fact I spoke basic Xitsonga to them. The purpose of these observations was to generate small stories nested with the bigger narratives generated by the interviews. Box 6 describes the observation procedures of the clinics.

- i) After receiving permission from the district manager and provincial ethics committee granted, the researcher arranged a general meeting with staff in advance to let them know that an observation as part of a research study is going to take place.*
- ii) An information poster was displayed in each facility to let staff and patients know about the research.*
- iii) The researcher was identified by a clear ID badge and the fieldworker an Agincourt fieldwork T-shirt.*
- v) The researcher will make it clear that she is not clinically trained.*
- vi) In the event of observing professional practice that is of concern or a patient in distress, the researcher will speak to a senior member of the research team or other relevant member of university staff for advice.*

Box 6. Procedures for clinic research observations

Obtaining informed consent for consultation observations

Oral consent to observe routine consultations was provided by the nurse and patient. This experience allowed me to understand the patient-health-worker face-to-face clinical process.

There were no audio recordings of any brief conversations. Only field notes were taken and these did not include any personal identifiers. Data from observations were analysed together with the interview responses.

Vutivi participant list

The participant groups were specifically chosen to answer Research Questions 2-4.

Interview schedules are in Appendix 10.

Table 15. Participant list and total number of people interviewed in the Vutivi study, including recruitment and interview location

Phase	Participant Groups Interviewed	Participants	Total	Recruitment and Interview location
Phase 1	Fieldwork preparation (General)	Pilot with nurses, gynaecologist, pregnant women and data clerk	-	1 District hospital, clinics and study site villages
Phase 2	Chronic disease patients	Vutivi patients with any chronic disease	51	4 clinics: 2 clinics in the study site, 2 clinics outside the study site
		Nkateko patients with chronic disease (hypertension)	18	3 clinics: 2 clinics within the study site, 1 clinic outside the study site
Phase 3	Pregnant women	Pregnant women interviewed	28	4 clinics: 2 clinics in the study site, 2 clinics outside the study site
		Pregnant women in focus groups	16	2 health facilities: 1 clinic and 1 district hospital
Phase 4	Health professionals	Nurses (clinic and hospital)	32	4 clinics: 2 clinics in the study site, 2 clinics outside the study site
		Doctors (Private/ Government)	11	1 District hospital, 1 private surgery in town
		Clinical associate students (mid-level health-worker)	4	1 District hospital
		Pharmacists	2	

Phase 5	Health-workers (additional)	Psychologist	1	1 District hospital, 1 private pharmacy in town, 1 health train, healers homes
		Optometrists	2	
		Occupational therapist	1	
		Traditional healers (indigenous)	2	
		Home-based carers (HBC)	4	
		Lay health-workers (LHW)	4	
Phase 6	Community members	Community members	14	1 study site village and 1 town on periphery of study site, next to district hospital
Phase 7	Policy-makers	Department of Health policy-makers: National	7	Johannesburg, Pretoria, Nelspruit and Cape Town, in person or via Skype*
		Department of Health policy-makers: Provincial	7	
		Department of Health policy-makers: District	1	
Phase 8	eHealth and mHealth experts	eHealth and mHealth experts (e.g. Mobile operators)	26	Johannesburg, Pretoria, Nelspruit and Cape Town, in person or via Skype
Total			231	

** For policy-makers and experts, the location of interviews was not important; rather it was about recruiting them for their particular role within the department/organisation.*

Phase 2. Patients with chronic disease

Patients with chronic disease were split into Vutivi and Nkateko patients.

Sample group: Vutivi patients with chronic disease

Sampling process for Vutivi patients with chronic disease and introductions

Patients were identified through the clinics. After morning prayers and singing, the clinic nurses introduced the fieldworker and myself to the patients waiting in the queue. The fieldworker gave a brief overview of the study in Xitsonga inviting them to participate. The nurses then gave the daily health talk to all patients before starting the consultations.

We aimed to sample patients for diversity of locality of residence, age and gender, for diversity of chronic disease and differing life experiences and uses of technology. Patients were recruited directly from the chronic disease queue on the day of the interview whilst waiting to see the nurse. For each planned recruitment day, there was a stratified quota of 5-10 patients. Sampling of patients was consecutive from the queue until all strata (several patients from each age group category) within the quota were filled or until there were no more patients. Patients waiting to see the nurse could not be interviewed until after their consultation.

Since this was not purposive patient sampling, diversity was by chance. It could be argued opportunistic sampling was not necessarily representative as we were relying on whichever patients were attending the clinic that day. However, we did interview at each clinic for a full week in duration, to cover a range of patients. Patient eligibility and exclusion criteria are detailed in Table 16.

Table 16. Eligibility and exclusion criteria for patients

<i>Eligibility criteria:</i> Men and women over 18-years, who were able and willing to provide informed consent.
<i>Exclusion criteria:</i> Patients who were very ill, reaching the end of life or under the influence of alcohol or drugs. The nurses judged factors that impacted upon the functioning of the participant to fully engage in the interview if necessary. Where possible, patients had thirty-minutes to an hour, whilst waiting in the queue, to consider if they wanted to participate.

Consent procedure for interviews

Consent was requested at the start of each interview. Informed written consent and research information leaflets were given to the potential participants both verbally and in writing in Xitsonga or English.

The consent form (Appendix 5) was read out to the potential participant. They were informed as to why the research was being undertaken and that they could contact the Agincourt Field Research Manager if a problem arose. Participation was voluntary at every stage and all information was kept strictly confidential. It was made clear to the participant that their data would remain anonymous. Consent was confirmed by a signature or inked thumbprint (for illiterate patients) (Photo 10). Separate consent was also requested to audio-record the interview (a Wits ethics regulation) using two digital recorders (one as a backup). The interview still went ahead if the participant was unwilling to be audio-recorded.

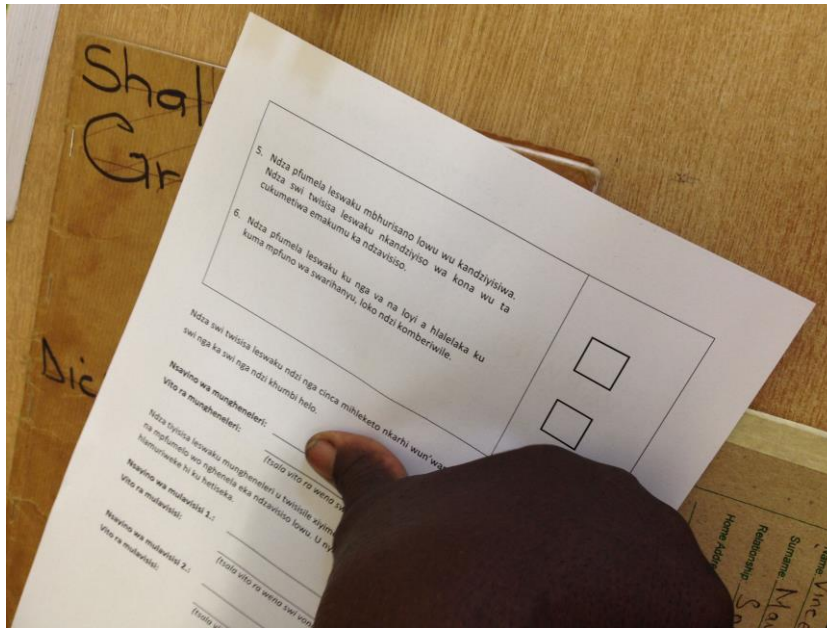


Photo 10. Illustration of inked thumbprint on patient consent forms

Patient demographic information

Basic demographic information was collected and recorded: including *names, gender, home village (not full address), other names known by, date of birth, cell phone number(s) and next of kin*. Gender was assessed visually. The disclosure of any chronic diseases was asked. This was recorded on a Demographic Information Form (Appendix 6) in a secure database made specifically for this study, by the Data Science team to ensure anonymity.

Patients were further asked if we could link their interview data to the Agincourt HDSS census to check if they had been enumerated the previous year. The linkage to the census allowed us to find out more about the individual and their household such as variables on household structure, employment and educational status. This data assisted in the interpretation of the interview data. If they agreed to be interviewed but did not agree to the linkage, they were still interviewed. We did not ask for Wits ethical approval to collect the person's individual South Africa National Identity Number (ID).

This made it harder to link patient data to the census dataset but other identifiers ensured exact matches were made.

Patient interview procedure

Interviews were conducted in private within clinic consulting rooms and conducted in English by myself with the aid of the fieldworker, who translated live into Xitsonga. This same process occurred for Nkateko patients and pregnant women. The interviews lasted 15-45 minutes. The interview schedule (Appendix 10. 2a) aided the structure of the interviews with ideas for prompts and probes. In order not to influence their responses, prompts were kept to a minimum and probing only used when a patient was non-responsive.

The interview schedule was adapted during the data collection process. We edited questions to make more cultural sense, for example ‘what do you do for employment?’ needed to be changed to ‘how do you earn money?’. These types of questions gave context and a deeper understanding about the person.

Interviews explored the experience of healthcare, meanings, uses and potential uses of digital technologies, within in the clinics and local community. The participant was encouraged to think imaginatively and laterally about technology use (including the Internet).

Data saturation of patients with chronic disease

Reoccurring themes started to arise during the final interviews. Data saturation was sufficiently reached by the fourth clinic. Nkateko patients were interviewed a few months later on similar topics, confirming data saturation had been reached.

Sample group: Nkateko patients with chronic disease

Following on from interviews with Vutivi patients, a second patient group and smaller cohort of patients, all with hypertension were interviewed. They were part of the intervention arm of the trial that include a mHealth component. Their experience and perceptions of receiving a digital clinic appointment reminder to assist with their chronic disease management was sought.

The Nkateko trial is called '*Treating hypertension in rural South Africa: A clinic-based lay health-worker to enhance integrated chronic care*'. It is a collaboration between Warwick and Wits (Trial registration number: ISRCTN12128227). The trial aims to test the effectiveness of clinic-based lay health-workers (LHWs) in supporting patient hypertension management. It is a pragmatic cluster randomised controlled trial with a primary outcome of improved uncontrolled hypertension in the population using LHWs to improve diagnosis, retention in care and adherence to treatment by patients. The Nkateko research team suggested that text-messaging could be used to improve medication adherence and health-related behaviour modification since many adults have access to mobile phones. The study protocol has been published by Thorogood *et al.* (2014).

Description of the mHealth component of the Nkateko trial

The intention was for clinic appointment reminders to be delivered via text-message remotely to the patient's mobile phone in either Xitsonga or English (depending on the language choice). An automated system was not used and the LHWs typed the messages from a message template. This included the patient's name and the clinic's name and the scheduled return date as the example below suggests.

*You are requested to come and collect your medication on (Makomberiwa ku ta teka maphilisi hi)(Date), here at the clinic tomorrow (mundzuku kwala).
Thanks (Inkomu) (LHW name)*



Photo 11. Photo of Nkateko employed LHW phoning a patient to remind them to come to their next appointment

Patients received the reminder messages or calls for the 15-month trial duration. Messages and calls contained only clinic appointment reminders and not health information for treatment adherence. The messages and calls were intended to improve communication between the clinic (healthcare system) and the patient.

The sampling process of clinics for Nkateko patients

The trial had four clinics involved in the intervention. By chance, three out of the four intervention clinics were not the same as Vutivi study clinics. This was important because we did not want to return to the same clinics to ensure we interviewed different patients. Therefore the three Nkateko clinics were purposively chosen. They were geographically dispersed, possibly widening the diversity of the sample. This was guided by the purposeful sampling principles of Patton (1990) combined with convenience sampling.

The criteria for eligibility were that the patients had high-blood pressure and were involved in the Nkateko trial arm exposed to the mHealth intervention. As with the Vutivi participants, we aimed for a diversity of age, gender, and technological experience.

Preparation for the Nkateko patient interviews

The Nkateko implementation manager accompanied me to the three intervention clinics, where we were introduced to the nurses on duty and the Nkateko LHWs. Interview dates were arranged for when Nkateko patients were booked in.

Nkateko interview procedure

The LHWs helped the fieldworker with recruitment by identifying which patients in the chronic queue were part of the trial. Consent was as per the Vutivi interviews. The LHWs or nurses were not present during the interview but did spontaneously enter the room if they needed a file or equipment. Usually the interview continued unless the patient wanted to pause.

The Nkateko trial team aimed to do exit interviews for both control and intervention clinic participants using a questionnaire. We ensured there was no repetition with each other's interview schedules. This study questioned the patient's experience of chronic illness (diagnosis and management), their adherence behaviour (how they remember their appointments and medication), general health and everyday life situation (Appendix 10. 2b).

I was solely responsible for data collection, data analysis and interpretation of qualitative data from the Nkateko patients. Collaborative sharing of interim findings with the trial team provided opportunities for feedback and generated deeper insights that informed the interpretation of the findings.

Phase 3. Pregnant women

The third patient group was women attending clinics for antenatal care.

The sampling process for pregnant women

We aimed to sample for different aged women at differing gestational ages and a range of parity (number of births). Women were recruited directly from the antenatal queue, at the same four clinics as Vutivi chronic disease patients. The difference in sample sizes between the patient groups was intentional because chronic disease patients were likely to vary more in terms of demographics and health conditions than antenatal women. Naturally there were far fewer pregnant women available at the clinics than patients. Also, there was overlap between the two groups, as many pregnant women were HIV positive and receiving long-term medication. When a pregnant woman also had a chronic disease, they were interviewed about both.

Interview procedure for pregnant women

Basic demographic data also included the number of months pregnant and gestational age at the first antenatal care visit, if known. Pregnant women were interviewed two-on-one, using the same procedure as with Vutivi chronic patients.

The interviews and FGDs with pregnant women centred on the use of mobile digital technology (Appendix 10. 3a). Pregnant women attending antenatal care were likely to have had experience of digital technology because they were generally younger. Women who are pregnant are often concerned about their health and that of their baby and likely to be interested in participating in research.

Focus group discussion procedure

After the completion of individual interviews, two further groups of pregnant women were interviewed in FGDs of 7-12 women at a study site health centre and a district hospital. They were asked the same questions as the two-on-one interviews. The purpose was to generate and stimulate a conversation between the women and see if new themes emerged through engaged group discussion (Appendix 10. 3b). The FGDs gave the pregnant women the opportunity to speak openly in an environment about their pregnancy and phone use, probably for the first time. FGDs were conducted in a combination of Xitsonga and English.

Access to the health centre was granted because Nkateko patient interviews had already taken place there. Access to the hospital was granted because the pilot was conducted there and hospital staff have a good relationship with Wits.

Phase 4: Health professionals: nurses and doctors

Nurses were interviewed at clinics and doctors at a district hospital. A district hospital was included because the level of care delivered in the outpatient department is mostly primary care. Interviews ascertained health professionals' use of technology for both social and work-related activities. All interviews were conducted in English.

Nurses

Sampling process for nurses in clinics

Nurses were recruited from the same four clinics as the Vutivi chronic disease patients but at a different time. Sampling of nurses was purposive for a diversity of duration, type of experience and work role. There were usually three-five nurses working at a clinic at any given time. We interviewed a hierarchy of nurses: senior, auxiliary and junior nurses. More nurses than doctors were interviewed because rural South African healthcare facilities are habitually run and managed by nurses, with infrequent visits by doctors.

Interview procedures for Nurses in clinics

The interviews were arranged at times that did not interfere with clinical work. Interviews with nurses lasted approximately 40-60 minutes. Both nurse and doctor interviews were broad in range, with emphasis on the barriers and enablers of the health system, with a technological interest (Appendix 10. 4a and b).

Doctors

Hospital sampling to recruit doctors

The hospital recruited was purposively chosen because of its location next to the Wits finance office, so rapport had already been built between the hospital doctors during the pilot.

Sampling process for doctors in the hospital

Permission was sought from the new hospital CEO to conduct interviews with government doctors. Snowball sampling allowed for doctors to suggest who should be interviewed next. Most doctors agreed to be interviewed in their work place before their shifts. Doctors were sent an introductory email with the study information inviting them to participate. Two out of the ten hospital doctors also had their own private practice and were interviewed under the remit of a public and private doctor. One private doctor was recruited from the town near to the hospital, by purposively going to his practice and inviting him to take part.

Interview procedures for doctors

Interviews with doctors were approximately 45-70 minutes. After some interviews, distressing stories were shared with the fieldworker and PhD supervisor, as psychologically, it was important to de-brief after hearing stories that carried upset or shock.

Phase 5: Additional health-workers

Sampling process to recruit health-workers

The sample was purposive as they were the only people in those roles available. The hospital health-workers included one hospital pharmacist, two optometrists and two mobile community outreach nurses. The private pharmacist was recruited from the pharmacy in the nearest large town. Traditional healers were recruited through gatekeepers. Community health-workers were recruited at the clinics.

Research questions focused on the health-workers' use of technology in their work place (Appendix 10. 5). Interviews were conducted in English and lasted 30-50 minutes.

Phase 6: Community members

Community members were interviewed in two environments, a village within the study site and a town next to the district hospital. The village and town were purposively chosen for ease of access and the diversity of people working at both locations. This enabled a comparison of village and town community members and their jobs.

Preparation for community member interviews

A member of the LINC team identified potential community members in the village and town. Sampling was at random since we relied on whoever was in their place of work on the day of recruitment. A diverse sample of community members was recruited at both locations (Table 17).

Table 17. List of community members' job roles

Village community members and job role
-Butcher

<ul style="list-style-type: none"> -Sewing shop staff -Airtime street seller and phone repair man -Fruit stall seller -Hairdresser -Plant seller -Food and goods shop seller -Farm fruit picker -Game ranger -Teachers -Community leader
Town community members and job role
<ul style="list-style-type: none"> -General goods store seller -Cell phone repair shop -Household goods street seller e.g. plants and straw mats -Computer training academy -High street cell phone shop selling new phones and airtime

A translator was paramount for this cohort. The original fieldworker was not used because she knew everyone in this village and was part of the community. It was a concern that conversations might become too casual. A female from another village outside of the HDSS was employed to act only as a live translator and did not transcribe the interviews.

Interview procedure for community members

Demographic information was not recorded, except their village name and job. Interviews were conducted in the person's shop or on the roadside because it was easy to access them during the day. Interviews lasted 10-35 minutes and were very ad hoc because they were working.

The purpose of these interviews was to inform the contextual background in Chapter 5 and give necessary context to the patient interviews. We wanted to learn about the

communities' livelihoods and where they used their phones or computers in their work and personal lives (Appendix 10. 6).

Observations in the community

An over-night village home-stay in a local family's home was organised by LINC (Box 7).

'A cattle herder helped me to find the family's house. Light was fading fast. I was taken through into a large room, unpainted with several black plastic chairs in a circle. Already sitting there was a neighbour called X (in her 60's), the grandfather wearing a Nike cap with a glass eye (story has it he had been attacked by a leopard at Skukuza in the 1950's when he worked there)... The daughter poured Coca-Cola for everyone. Her father told her to kneel because in their culture that is a sign of respect to the guests. There were three plates all with meali pap [ground maize flour].
I tried to sleep but the cattle were in their kraal (pen) right outside the window. Most cows have a noisy cowbell on so this chimed through the night, it was also near a full moon so very light outside. All the village dogs started barking that, went on for ages. I was shown a small green bucket, which I could use to urinate in and showed me in the morning where to put it. There was also a large bucket for washing with in the morning. The youngest daughter came with me to the clinic. It was school holidays. She sat on the wall listening to music on her basic phone.'

Box 7. Extract from village home-stay

The home-stay allowed for in-depth conversations over time with several family members about their phone use and observations of how they were using their phones whilst at home. The purpose was to also learn more about the Shangaan culture and home life by sharing food.

Phase 7: Policy-makers

The sample of policy-makers were the 'policy actors' (Lehmann & Gilson, 2013:358) or decision-makers within the government. They were recruited away from the study site from different parts of South Africa. Interviews were arranged with policy-makers

at the district, provincial and national levels of the South African government within the Department of Health.

Policy-makers were identified through reading policy documents, seeking expert advice from eHealth and mHealth experts and networking. Further sampling of policy-makers was reliant on goodwill and good-fortune. At the Public Health Association of South Africa conference (2013), a member of the NDOH was approached to begin snowball sampling. This process unexpectedly allowed for the sample size to be larger than anticipated.

Interview procedure with policy-makers

The interviews explored a range of topics including policies, challenges to implementation, barriers and enablers, health system needs and solutions (Appendix 10. 7). Each interview was audio-recorded and conducted in English. In addition to interviewing the policy-makers, it was necessary to read and understand relevant policies before and after the interviews. These were described in Chapter 2 and are analysed in Chapter 7.

Interviews were conducted at the national headquarters of the NDOH in the city of Tshwane (Pretoria) and the provincial offices in Mbombela (Nelspruit), or over telephone or Skype. Interviews lasted for 60-90 minutes.

Phase 8: eHealth and mHealth experts

Experts were members of the government-formed South African mHealth Task-Team, NGOs, for-profit commercial companies, parastatal organisations, consultants and

employees involved in the implementation of mHealth initiatives. Experts were identified through observation of the locality, local directories, through a stakeholder mapping exercise assisted by policy-makers network sampling analysis. The initial list of individuals and organisations was expanded through snowball sampling until a point of saturation was achieved. This took longer than anticipated because of the complexity of the topic.

Interview procedures with eHealth and mHealth experts

Interviews were undertaken face-to-face where possible or over the telephone or Skype. Interviews were conducted in the same manner as policy-makers. Experts were asked directly about their work roles in relation to digital health in South Africa (Appendix 10. 8). Interviews lasted 75-90 minutes, longer in duration than other participant groups.

Future healthcare technology

Experts also included interviews with GE Healthcare, one of the PhD funders. Interviews took place with GE Healthcare UK Ltd. in 2012 and 2013 and GE Healthcare South Africa Ltd. in 2014. The reason for this was to discuss topics such as future health technology (horizon-scanning) and the feasibility of these in rural settings. This informed the understanding of what likely technologies were being designed and deployed in other low-resource settings. There was strictly no commitment to do any field trials of GE's technology devices, as stipulated in the studentship contract.

4.5 Quantitative method procedure

Secondary quantitative data analysis using the Research Unit's 2014 census was undertaken to:

- a) Compare the linked study sample with the study site population using demographic statistics such as age and gender, to determine how representative the study sample was.
- b) To link the Vutivi demographic data to the census variables, to extend what is known about the individual patient. The process of seeking permission from the patients for this, is described in Phase 1.

Permission was granted by the Research Unit's Data Science Team to use the quantitative data. They created an anonymised dataset to include the adult population over 18 years and three requested census variables in Box 8.

Variables with individual units of analysis

-*Education status* (none/primary/secondary/tertiary/unknown).

This was coded by the highest grade a person reached categorised by education level.

-*Grant status* (child support/disability/not receiving any grant/old age grant).

Variables with household units of analysis

-*Asset ownership* (electricity/radio/television/fixed line phone/cell phone).

-*Socio Economic Status (SES)* is the index of assets, calculated from 'modern assets', 'livestock assets', 'power supply', 'water and sanitation', and 'dwelling structure'.

SES ranges from 0 to 5, 0 being the lowest asset indicator.

Box 8. List of the three census variables and their descriptions from the HDSS dataset

4.6 d) Fieldworker, ethics and research challenges

Fieldworker's role within the Vutivi study

Training and supervision of the fieldworker

The LINC team recruited an experienced multi-lingual qualitative female fieldworker aged between 30-40 years. She is Xitsonga-speaking and familiar with the communities as she lives in a study site village. A one-day workshop at the Agincourt office focused on research ethics, methodology, interviewing techniques and role-playing the interview process. We discussed the consent forms and training on the computerised database for patient demographics.

The language used in the interviews

The fieldworker acted as a live translator for interviews with patients and pregnant women. Interviews were often conducted in a combination of languages such as English and Xitsonga. The fieldworker knew when the Xitsonga spoken was that of Mozambican Xitsonga rather than South African Xitsonga because of the dialect. This helped explain why some of the findings from Mozambicans were different from some of the South African patients such as educational level and technology use.

It had not been anticipated that some patients would speak isiZulu, SiSwati or isiXhosa. The fieldworker was proficient in nine official South African languages and was therefore willing to switch language depending on the participant's preference. This was a major benefit to the study. Some patients preferred to speak directly to me in English rather than using the fieldworker. This became problematic when the person could not speak sufficient English.

Transcription and translation of interviews

The fieldworker transcribed all interview audio-recordings of patient and pregnant women. She transcribed each interview verbatim into English soon after the live interviews took place.

Samples of the interviews were discussed with the fieldworker, focussing particularly on key words to ensure the participant's intended meaning was understood. The process of checking interpretation started early on. Secondly, to ensure the reliability of the transcriptions, an independent person was employed to transcribe ten per cent of all patient interviews. The person was purposively chosen as he was not from the study site but had prior experience working as a professional Xitsonga-English translator. He signed a confidentiality form and was given the audio-recordings on a password protected USB stick, which was returned at the end of the study. The fieldworker's transcripts and the independent person's transcripts were almost an identical match.

Discussion of data with the fieldworker post-interviews

We oversampled at the first clinic on purpose so that the first five interviews acted as a form of observation and feedback session. We then had a break to discuss how these 'practice' interviews went. It was agreed these would be included in the final quota. After each day of interviewing, we would discuss the strengths and weaknesses of the research that day. We ran through my written interview notes to clarify issues and used the travelling time together to discuss cultural aspects related to health. Interview and field notes were compared with the final transcripts.

Ethical considerations

Ethics and approvals

This study fulfilled the ethical requirements of:

- Two universities: The University of Warwick Biomedical and Scientific Research Ethics Sub-Committee (REGO-2013-082) and the University of the Witwatersrand Medical Human Research Ethics Committee (M130411) (Appendix 1. A-B).
- Provincial and district ethics committees: The Mpumalanga Provincial Research and Ethics Committee (Department of Health) and Bushbuckridge sub-district (Department of Health) (Appendix 1. C-D).
- Permission to access the HDSS and census data was granted by Prof. Stephen Tollman (Appendix 1. E).

The ethics process was monitored throughout the fieldwork by all three supervisors: Prof. Griffiths Dr Goudge and Dr Gómez-Olivé. They are all actively involved in research at the Agincourt HDSS.

Right of withdrawal

Participants were able to withdraw from the research process at any time and can still withdraw retrospectively. Any data already recorded about that individual participant will be destroyed.

Data confidentiality

In resource-poor settings, maintaining anonymity and ensuring privacy are key ethical and methodological concerns (Cluver, 2006). At the start of the study the fieldworker

consented to keep all data confidential. All efforts were made to ensure that data confidentiality was maintained, especially when a chronic disease was disclosed. HIV is known to be a stigmatised illness and disclosure is still uncommon (Okoror *et al.*, 2014).

Electronic data files containing identifying details were kept secure and spreadsheets were password protected. The database of demographic information was encrypted.

Participant confidentiality and data security

To protect all participants' anonymity, each participant was given a coded number at the time of interview. No real names or contact details are stated in this study. The findings do not identify the health facilities by name.

The data requested from the census was already anonymised from the database. The anonymised databases are encoded using a 23-digit key that produces a five alpha code. The Agincourt Data Manager is the only person who has the key to un-code the identifiers. Consequently, there are no identifiers that could be used to link the information with any participants.

Location and security arrangements

The specific location of the electronically stored data (including text and audio files) was on the researcher's Medical School owned laptop (password protected) and backed-up on an external password protected hard-drive. Physical documents (paper records) were stored in a locked filing cabinet in a secure room.

Remuneration

It is not the within Agincourt policy to make direct payments to participants. No remuneration for taking part was given, including transport costs as patients were already attending the clinic. The incentive to take part in the Vutivi study was high because it was a short one-off interview.

Since participants were recruited at the clinic, it was not possible to send each patient a thank you letter individually but we delivered a thank you poster and letter to the clinic a few weeks after the interviews took place. Nurses were given a gift of biscuits for helping with the smooth running of the study. In only one instance did we face the challenge of being asked by the nurses for a computer. However this was because a neighbouring clinic had just received delivery of a new computer from the Department of Health.

4.7 Fieldwork challenges

Fieldwork challenges caused by political and environmental factors are described in Table 18.

Table 18. Political and environmental factors that caused challenges to the fieldwork process

Political and Environmental factors	Example
<i>Strikes:</i>	During the collection of data there were a number of provincial strikes by taxi drivers complaining about the state of the roads because large trucks transporting natural resources were damaging them. This meant staff could not always get to the clinic, as roads were closed because tyres and branches were lit and in flames and blocking cars from passing. Strikes were also taking place because of a lack of services such as running water in the study site causing distribution. Strikes meant we had to re-schedule some interviews at clinics.

<i>Political tension (National Government Elections):</i>	Fieldwork took place during the six-month run up to the national general election. This meant sometimes many of the ANC cars were patrolling the villages, with huge tannoy systems telling the people what the ANC will do in the next government. This did not affect fieldwork from taking place but it did mean people had perhaps a different feeling about government and what they wanted to see with the newly elected leader. President Jacob Zuma, GCB Head of the ANC, remained in power.
<i>Weather:</i>	<p>The start of fieldwork took place during the hot, rainy summer season. This meant some of the dirt roads were impassable with a normal vehicle. Fortunately a 4x4 was used to transport the fieldworker and myself. The heat made interviewing some of the chronic patients unbearable for them and us. One participant almost passed out and we had to find water quickly, which is not easy when the taps were out of service and there is no running water at the facility, other than a storage tank outside.</p> <p>Due to the torrential rain, thunder and lightening storms, often the clinics had power cuts during the mornings, which meant with a black sky outside and no lightening inside, the clinics were very dark. During several interviews this made it hard to see the interview schedules. We asked the nurses how they felt consulting in these conditions, especially dispensing medication from the pharmacy cupboard. They said they are now used to it and it did not seem to bother them. No clinics had generators.</p>
<i>Power cuts:</i>	<p>South Africa is experiencing a national shortage of electricity. Therefore often in the evenings when we returned from fieldwork there was no electricity because of a power outage. This meant using a laptop with limited battery by candlelight was not always possible. Photographs were taken of hand written paper notes as a back-up when typing them up straight away was not possible. The country's national electricity provider Eskom was unable to provide electricity for the province for many hours each week. Citizens were advised how long the power outage would last for but sometimes they were unexpected. Power cuts resulted in telephones lines, faxes, and computers to stop working.</p> <p>Power outages would also effect the mobile phone signal and often signal would drop to zero making it impossible to make a phone call or send a text-message, or find 3G. This led to an impact on the fieldwork because it was difficult to contact the fieldworker at certain times to make arrangements.</p>

<i>Fires:</i>	Bush fires during the winter were a concern especially when there was a fire on the neighbouring farm, we made sure all consent forms and notes were kept at the Agincourt office at the district hospital in a fire-proof safe away from my residence. Known risks were averted.
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4.8 e) Methodological strengths and limitations

Methodological strengths of the Vutivi study

Study strengths included a good sample size and range of participants necessary to conduct a critical analysis.

The method of recording data by writing notes, taking audio-recordings, transcriptions and manually and digitally coding was a strength of the quality of data obtained.

The study sample is partly nested within the Agincourt HDSS population. An advantage of using the HDSS data was the availability of longitudinal demographic data to allow for comparisons between the study sample and the study site population.

The advantages of mixed-methods research enhanced the validity of findings to offset individual method weaknesses. This provided stronger inferences to answer the different research questions. Overall, the quantitative statistics helped the interpretation of the qualitative findings and provided richer, more comprehensive narratives.

Methodological limitations of the Vutivi study

This qualitative study has a number of methodological limitations. A longitudinal study would have been beneficial to track changes in technological use over time and conduct follow-up interviews but this required more time than allowed for a doctorate.

It would have been valuable to interview people in their homes. This would have given an insight into their lives by directly observing them using their phones in their home environment. It was not possible to sample door-to-door because a single researcher and fieldworker conducted the study. People were probably more willing to speak in the clinic environment because it was private (with no family members or friends present).

4.9 f) Analysis strategy of primary qualitative data

All interview and FGD transcripts and field notes were read and re-read by myself. Apart from the patient transcripts (transcribed, typed and translated by the fieldworker, mostly in Xitsonga), all English interview recordings were transcribed by myself. This process allowed for reflection and re-listening to the interviews. Where audio-recordings were of poor quality due to background noise or sound interference, a data typist was employed to re-type them. This allowed for two versions to be compared especially for inaudible words. This was supplemented with notes made during the interview.

Analysis procedure

Initial analysis began during fieldwork when re-listening the interviews. Notes were made about any emerging themes that were complimentary or antagonistic to one another. Comparisons between participant groups and within groups occurred early on. Analysis involved immersion in the data over time and was inductive in nature.

Coding frame used for data analysis

A preliminary coding framework (Appendix 8) was created based on the topics covered in the interview schedules and additional codes were added based on emerging themes. The coding framework was formed to develop preliminary descriptive codes and macro-themes prior to using computer software to manage and code the data. These were merged to build an integrated explanation, interpreted in the light of the literature and the theories presented in the theoretical framework (Rubin & Rubin, 2011).

Software used for data management and analysis

To facilitate and manage the quantity of interview data effectively, a qualitative software tool called QSR International NVivo (version 10) was used. NVivo was chosen over other data management programmes because of prior experience and training. The main functionality of NVivo was to store and separate different sections of each interview under the same theme (node) so that all relevant data was together. The coding framework with initial descriptive codes was used alongside NVivo to electronically code the high-level themes. Other topical and emergent sub-codes developed as a result of this process. The annotation functionality was used when a discussion idea was raised whilst coding. Overarching themes (collection of main themes) became apparent once all data was coded. There were 24 main themes, 118 specific sub-themes and five main overarching themes. A total of 231 interview transcripts were coded. NVivo reports were generated and compared to identify key themes with all quotes related to each code (under each participant group)

Qualitative analysis techniques

Thematic and comparative analysis techniques were used.

Thematic analysis of qualitative data

Thematic coding of the data allowed for the merging of responses from all participant groups to triangulate data from the interviews, FGDs, observations and policy analysis (Patton, 1999).

Thematic analysis of all qualitative data was undertaken initially. Key themes were identified from the case study. A systematic search for patterns in the data to provide an illuminating description of the phenomenon occurred. This technique resulted in the development of meaningful themes providing ‘rich insights into complex phenomena to expand or test existing theory’ and a ‘15-point checklist of criteria for a good thematic analysis’ was applied to ensure quality of the analysis (Braun & Clarke, 2006:77). Uncommon or oppositional responses (anomalies) were noted and a potential explanation sought. An emergent approach was used to build theory from emerging data.

Comparative analysis

Comparative analysis was used in the development of theory. Data from different settings or participant groups at the same point in time was examined to identify similarities and differences. A final synthesis of results using overarching themes is illustrated in a model (Chapter 8).

Respondent validation or ‘member checking’ (Lincoln & Guba, 1985) was included in the analysis; where by a member of the community reviewed the findings to ensure that the conversations had been interpreted correctly. An audit trail of data collection was kept for transparency of the process and analysis in the form of a research diary.

Participants' quote selection

For each key analytic theme, data extracts were identified on the basis of being representative or interesting. The decision to include the selected quotes was made that if two people said something similar but with variations, both accounts were reported. If the same theme was discussed within a different context, both views were accounted for. This ensured the nuances and subtleties in the data were not neglected. Data selection covers a range of data chosen to illustrate and clarify diversity amongst responses.

Reflexivity of the research process occurred throughout the entire fieldwork year. Everyday, time was taken to reflect on what had been seen and heard. It was recognised when analysing and interpreting the data, that I am a white female, with a weak South African accent and associated with Wits.

Analysis strategy of secondary quantitative data

The descriptive statistical analysis was undertaken using Microsoft Excel 2011 to show variation. Data was from both the population census and the patient demographics collected during the interviews. In Chapter 5, an analysis of patient socio-demographics is presented to demonstrate the *gender, age group, age range, gestational range and chronic disease type* in tables including the standard deviation (SD) range. Comparative demographics between study participants and study site sample was analysed. For example, a bar chart illustrates a comparison of age categories. Descriptive statistics on the linked participants' census variables included *social grants, current household assets, educational stage and socioeconomic status (SES)*. A table to demonstrate the number and percentage of participants that receive a social grant and the level of

education achieved is given. A line graph illustrates the SES to demonstrate mobile phone ownership.

4.10 g) Research dissemination

Dissemination of Vutivi research findings

The importance of demonstrating sound dissemination of research findings to all study participants is paramount. Research results are being disseminated through the following channels (Table 19).

Table 19. Proposed dissemination channels of the Vutivi study's research findings

LINC	<p>Through the LINC team to provide community feedback. Of up most importance is to tell the community and people we researched, about the findings in a way that is understood and has a meaning and significance to them and their lives. Results will be disseminated to the community through Community Development Forum meetings and at the annual census feedback day in all study site villages.</p> <p>A presentation was given to seven nurses at the Agincourt office in June 2016 accompanied by a member of the LINC team to ensure the correct protocol of delivery research findings were met. Nurses were given petrol money for their transport costs and a soft lunch after the PowerPoint presentation was delivered and a hand-out of the slides to take back to their clinics. A general discussion and question and answer session followed.</p>
Emails	All eHealth and mHealth experts expressed great interest in the findings of this project and will be emailed a summary. This can be extended to interested academics working in the field, and other government departments. HealthEnabled will publish the findings in their weekly South African mHealth group email.
Publication	Through publication in open-access peer-reviewed journals (a publication strategy has been discussed with supervisors) as stipulated by the ESRC.
Policy brief	A short policy brief will be written for the Department of Health, South Africa.
Reports	<p>A report for the Mpumalanga Province Research Committee.</p> <p>A report to the ESRC (funders) to show research quality and impact.</p>

	<p>A written report and oral presentation will be given to GE Healthcare Ltd. (UK) at their head office (three annual reports have already been submitted).</p> <p>A report for the Agincourt Management Team including the fieldworkers.</p>
Presentation	<p>An oral presentation to the Agincourt office team with the invitation extending to local doctors and other researchers.</p> <p>An oral presentation was given at the ICT4Health conference, at the University of Stellenbosch (November, 2015) to all government ministers and people/players working in eHealth and mHealth in South Africa. This opportunity allowed me to be part of the government's meeting in setting the agenda for eHealth and mHealth in South Africa over the next five years.</p>
Website	The summary of findings will be made publically accessible on the Warwick Medical School website (ePortfolio) and Agincourt website.
Printed thesis in library	An electronic thesis will be publically available through Warwick's online archive (WRAP) post-submission.
Researchfish	Impact findings resulting from the Research Council funding have been submitted to the Researchfish website.

Timely publication of results to ensure relevance is of particular importance in the field of eHealth and mHealth because of the speed at which development, design and implementation of technologies ensues. It is an ethical responsibility of applied empirical research in the developing world to ensure that findings are quickly made available to relevant stakeholders. Academic papers and PhD theses are largely inaccessible to South African healthcare staff and policy-makers. Every attempt will be made to make this research easily accessible.

The current political climate should aid the uptake of research findings, especially as South Africa has recently launched the mHealth Strategy and NHI White Paper combined with the popularity of the buzzwords 'eHealth and mHealth', but slowly becoming commonplace. In addition, the WHO (2016) has recently issued a brief

statement on ‘mHealth: use of mobile wireless technology for public health’ (WHO, 2016).

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The following results chapters will report findings resulting from the data collection and analysis strategy described in this chapter. Chapter 5 will give a broad overview of the contextual results. Chapter 6 will then address Research Question 2 and 3, followed by Chapter 7 to address Research Question 4.

Chapter 5

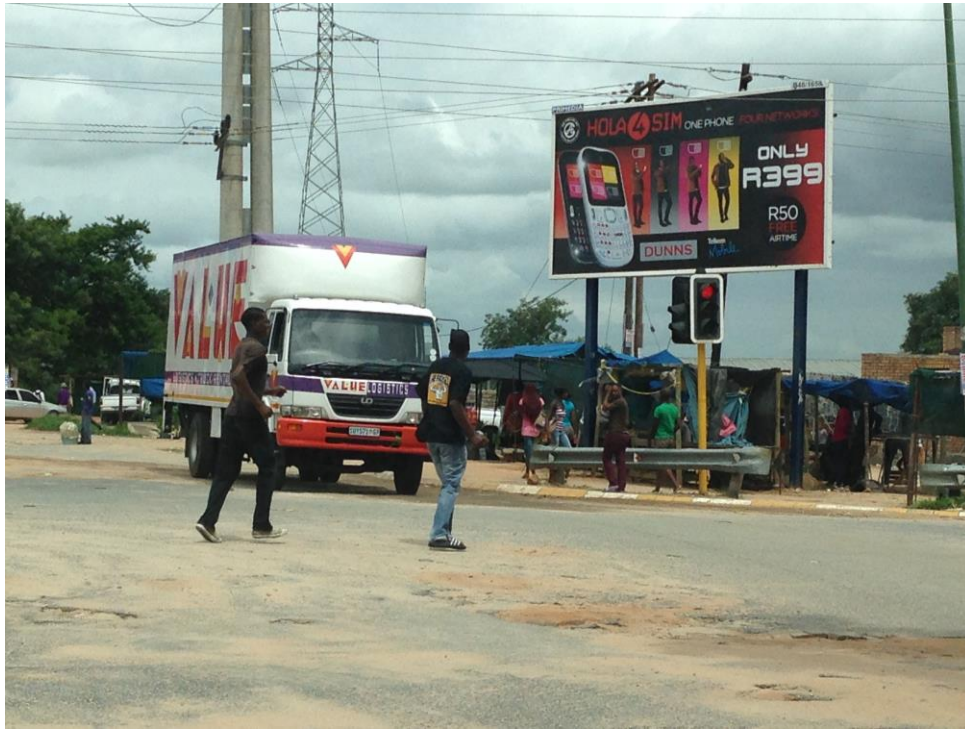


Photo 12. Mobile phone advertisement above a market in town on periphery of study site

Chapter 5: Contextual results – Description of patients’ lives, health-workers’ work roles and primary care environment

5.1 Overview of the three results chapters

This thesis contains three results chapters (5-7).

Empirical research from the embedded case study in the Agincourt field site: broad context

Chapter 5: presents the background context. The purpose of Chapter 5 is to provide necessary detail to understand the narrower context, emerging themes and theories in Chapters 6 and 7.

Empirical research from the embedded case study in the Agincourt field site: how patients and health-workers use their phones

Chapter 6: presents the main findings for Research Questions 2-3 – the current and future use of digital health technology within the rural field site.

Empirical research from the overall case study of South African policy

Chapter 7: presents the main findings for Research Question 4 – the top-down analysis surrounding the politics around eHealth and mHealth in South Africa more generally.

Discussion of overarching themes with policy recommendations

Chapter 8: links these results chapters by discussing what is happening on the ground and the general eHealth and mHealth environment with recommendations of how to move forward.

Structure of Chapter 5: broad contextual results

Section 1: The quantitative contextual findings are separated into:

- Summary of demographics
- Comparative demographics
- Census variables

Section 2: An overview of patients' life situations, the context of general phone and computer use by patients and health-workers (non-health related).

Section 3: An overview of the health system including the clinic and hospital environment and the challenges accompanying rural healthcare.

5.2 Section 1: Quantitative contextual results of patients and health-workers

Summary of information for patients and health-workers

The basic information of patients and health-workers is described in Box 9.

Patients

Language - Patient interviews were conducted in Xitsonga (67%), English (14%), isiXhosa (4%), SiSwati (4%), isiZulu (2%) or dual-language (9%).

Race/nationality - Patients were all black African South Africans, Swazis, and Mozambicans.

Consent - Everyone was willing to be interviewed and gave consent. One patient became too ill during the interview it ceased. There were no refusals to take part. Many more people wanted to be interviewed than there was capacity for. About half of patients preferred to give an inked thumbprint than penned signature.

Phone ownership - All patients and health-workers interviewed owned a phone (100%).

Airtime (pre-paid mobile phone credit) - Of the total 113 patients, only 30 per cent of them had airtime credit at the time of interview and only 10 per cent were active Internet-users. Airtime vouchers are sold in denominations of R5 to R180, with the majority of participants saying they bought between R5-R30 airtime. A loaf of bread

in South Africa can range from R10-17 at anyone time. One text-message costs approximately R0.50 and calls costs between R0.40-R0.80 per minute but this can vary depending on the mobile operator deals. Data bundles can be purchased: 5MB for R4/ 50MB for R25 etc. Price varies between providers.

Health-workers

Race/nationality - Nurses were all Black African. There was an equal ratio of black/white South African doctors and two doctors were British.

Qualifications – Nurses were junior up to professional. Three doctors were qualified junior doctors, six were in the middle of their career and two were near to retirement. Due to the shortage of specialists at the hospital, most doctors worked in all wards and outpatients.

Box 9. Summary of basic patient and health-workers demographics from the Vutivi study

Summary of demographic tables for patient groups

The following tables summarise the demographic characteristics of the patients and pregnant women.

Table 20. Socio-demographic characteristics for study patient samples and HDSS study site

	Vutivi chronic disease patients n=54 (%)	Nkateko chronic disease patients n=18 (%)	Vutivi pregnant women (Interview) n=28 (%)	Vutivi pregnant women (FGDs) n=16 (%)	Study site population n=56955 (%)
Gender % (n)					
Female	79.6 (43)	72.2 (13)	100 (28)	100 (16)	53.6 (30536)
Male	20.4 (11)	27.8 (5)			46.3 (26419)
Age group % (n)					

18-24	7.4 (4)		57.1 (16)	68.8 (11)	21.9 (12455)
25-29	5.6 (3)		14.3 (4)	12.5 (2)	17.8 (10112)
30-39	24.1 (13)	5.6 (1)	25.0 (7)	18.8 (3)	24.7 (14076)
40-49	16.7 (9)		3.6 (1)		14.9 (8464)
50-59	20.4 (11)	27.8 (5)			9.2 (5248)
60-69	20.4 (11)	27.8 (5)			5.5 (3109)
70-79	3.7 (2)	5.6 (1)			3.5 (2019)
>80	1.9 (1)	33.3 (6)			2.6 (1472)
Age range (years)					
Min	20	36	18	18	18
Max	80	88	40	37	41
Average	46.7	67.7	25.3	24.2	37.8
SD	14.7	15.5	6.2	6.3	16.1
Gestational age (months)					
Min			2	5	
Max			9	9	
Average			6	7	
Chronic disease type % (n)					
HIV	63.0 (34)		17.9 (5)		
Hyper-tension	38.9 (21)	100 (18)	3.6 (1)		
Diabetes	13.2 (7)				
Epilepsy	5.7 (3)				
Mental	1.9 (1)				
Asthma	1.9 (1)				

Demographics for Vutivi chronic disease patients

Sample gender was heavily weighted towards females. Men and women ranged in age from 18-80 years. The average age of chronic disease patients was 46 years (SD 14.7). The most prevalent chronic disease within this sample was HIV (62%). HIV is one of the most prevalent diseases in the study site. This high percentage is in line with previous studies.

Demographics for Vutivi pregnant women

The average gestational age was six months at the time of interview. A total of 21.4 per cent of pregnant women also had a chronic disease (HIV or TB) that they made reference to but the true percentage could be higher. The majority of women were aged between 18 and 24 years and the average age was 25 years.

Demographics for Vutivi pregnant women from the FGDs

The 16 women in the FGDs had of an average age of 24 years (SD 6.2), similar to the 28 pregnant women interviewed individually. The average gestational age was 7-months. This was largely because the majority of women had not sought antenatal care early into their pregnancy. Women who were 1-4 months pregnant did not participate, perhaps for this reason.

Demographics for Nkateko chronic disease patients

Nkateko sample gender was heavily weighted towards females, as with the Vutivi patients. Men and women ranged from 18-88 years. The average age of Nkateko patients was 67 years (SD 15.5) with hypertension, more common in adults over 50 years (Lloyd-Sherlock *et al.*, 2014). Several patients described co-morbidity (typically diabetes or HIV).

Comparative demographics between study participants and study site sample

The following tables compare the study sample to the study site population (>18 years). This is to determine how representative the sample is in relation to the study site population. The study site population was defined as the total number of individuals >18 years, under surveillance on 1st of January 2014.

The descriptive analysis of study population is broken down by age in Table 20. This table indicates older people >50 years were over represented in the study sample. The >50 year olds only account for about 20 per cent of the study population, however a high percentage of people >50 years have not necessarily been diagnosed with a chronic disease.

A comparison was made with the study site population gender with that of study participants. However it must be considered that the census is very large compared to the study sample. The population sample was over-representative of females and under-representative for males. Due to labour migration, there are more females than males in the study site. The sample reflects this as more females than males were interviewed in both chronic sample groups.

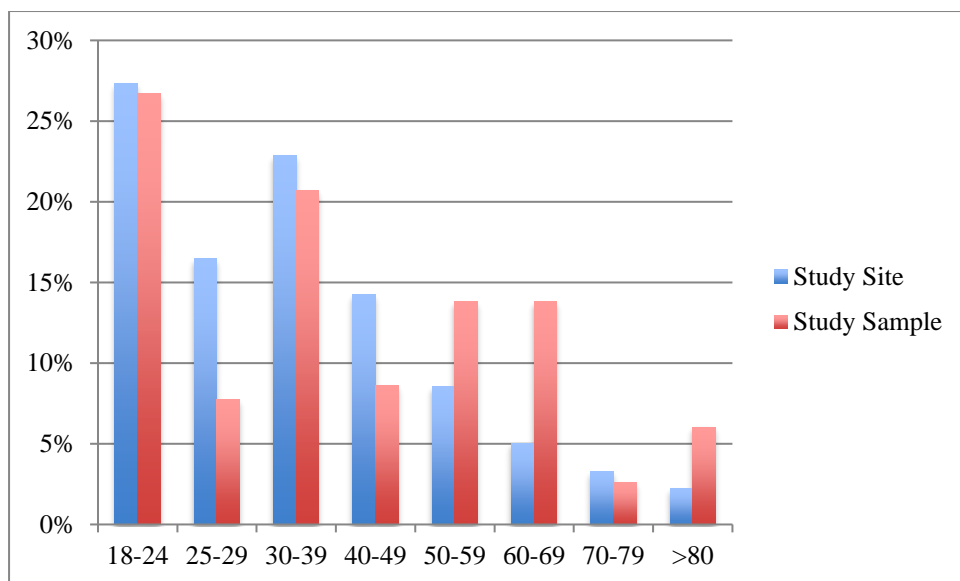


Figure 18. The comparative age categories between study sample and study site population

The size of the >70 years study cohort was representative of the study site population (Figure 18). The number of 18-24 years in the study site was accurately sampled. However, this sample considerably under represents 25-29 year olds, who may be temporary labour migrants. The census accounts for them being in the site population cohort because their permanent home is still considered to be within the HDSS although they may not necessarily be living there for more than six months of a calendar year.

Study participants and census variables

This section describes the linkage of participants to the census database with demographic variables used: *social grants, current household assets, educational stage and SES*. All participants agreed for their demographic data to be linked to the study site database, if they resided in the HDSS. Participants were linked using the following demographic information: *name, other name, date of birth, cell phone number, village and next of kin*. Some could not be linked because they gave inaccurate data (wrong

date of birth or spelling of name), or who had just in-migrated into the study site and were not already registered in the census.

For the linked participants, further descriptive statistics were accessed to understand more about them. The total number of the study sample that could be successfully linked to the HDSS database was 49 out of 113 participants: Vutivi chronic n=17, Nkateko n=12, Vutivi pregnant (interviews) n=11 and Vutivi pregnant (FGDs) n=9.

Table 21. Social grants and education status of linked study participants

Linked participants % (n)	
Grant status	
Child support	2.0 (1)
Disability	6.1 (3)
Not receiving any grant	55.0 (27)
Pension	22.4 (11)
Education status	
None	16.3 (8)
Primary	18.4 (9)
Secondary	32.7 (16)
Tertiary	2.0 (1)
Unknown	30.6 (15)

Social grants status: The majority of linked participants living in the study site were not receiving any social grant. Those that were, commonly received the pension grant. Pregnant women with children reported receiving child grants.

Education status: 32 per cent of linked participants had secondary schooling and 16 per cent has none. This could be higher, given not all participants were able to be linked. Unknown data from the census can often be attributed to the household respondent not knowing the responses for all household members, at the time of the census.

Table 22. Household asset status of linked study participants compared to study site population

Household	Linked	Study site
asset *	participants % (n)	population % (n)
Electricity	71.4 (35)	82.1 (46753)
Radio	24.5 (12)	17.0 (9698)
Television	67.3 (33)	74.9 (42677)
Fixed line	4.1 (2)	0.8 (480)
Mobile phone	71.4 (35)	83.4 (47520)

**Only the household asset variable was compared to the study site population because of its relevance to this research.*

Household assets: The percentage of households that had electricity for lighting is 71 per cent. 24 per cent of households owned a radio, although access to a radio has now been increased by the ownership of mobile phones with a radio function. Two thirds (67%) owned a television, in line with the percentage that have electricity to power the television. Only 4 per cent of households had a fixed-line phone in comparison to 71 per cent who had one or more mobile phones.

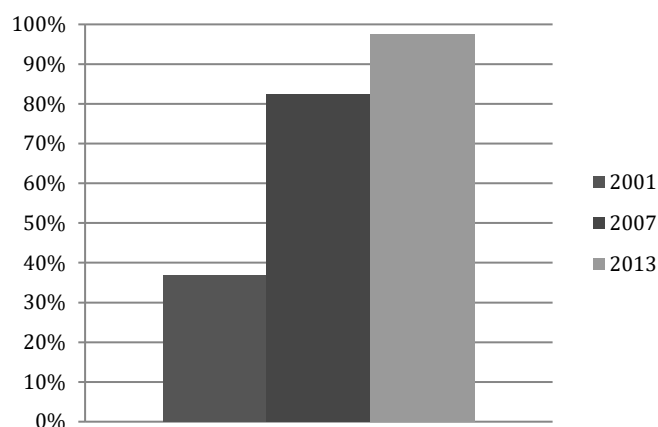


Figure 19. Percentage of households owning mobile phones in the Agincourt HDSS study site (Agincourt, 2014a)

This bar chart in Figure 19, from the Village Fact Sheet (Agincourt, 2014a) illustrates that in 2013, 97 per cent of HDSS households owned mobile phones. The graph illustrates a two and a half-fold increase in mobile phone ownership from 2001-2013.

Table 23. The percentage of study site population with various assets by SES index

SES	TV	Radio	Fixed Phone	Mobile Phone
0-1	0	0	0	0
1-2	32	9	1	178
2-3	175	34	2	197
3-4	199	85	5	200
4-5	100	0	0	100

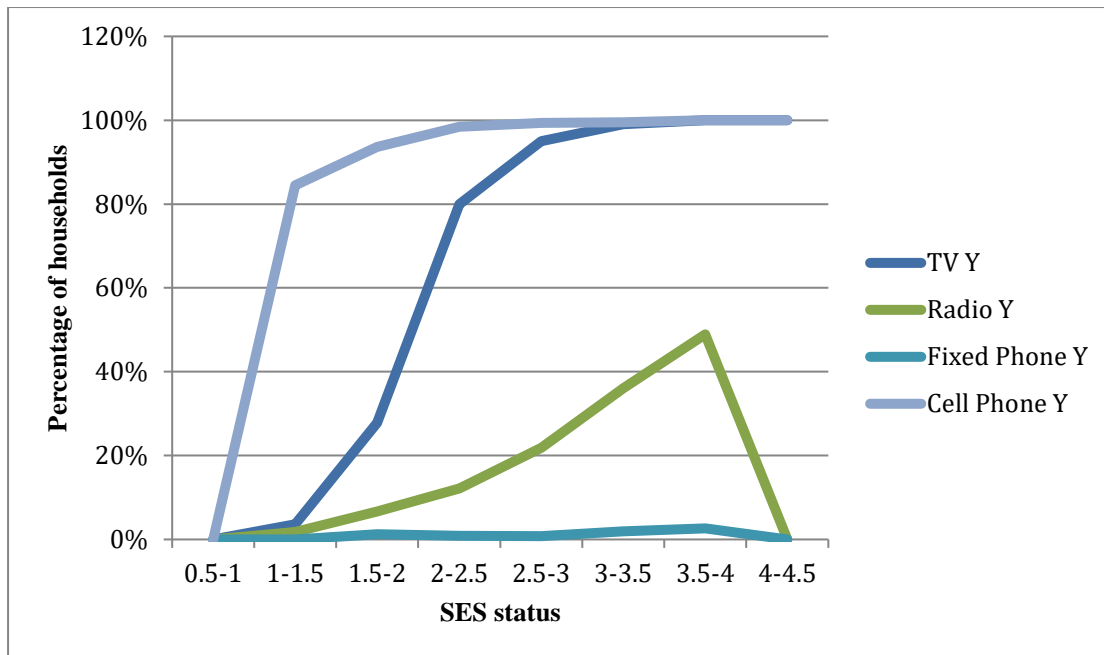


Figure 20. Percentage of household asset status by SES status

The graph in Figure 20 and Table 23 illustrate the vast difference in mobile phone ownership compared to fixed-line phones. Mobile phone ownership per household is ubiquitous across all SES groups, whereas other assets, such as television ownership, are not. This indicates that no matter the SES indicator, it is highly likely a mobile phone is owned, compared to other assets, which SES is dependent on. Thus a mobile phone is a utility rather than a luxury.

The quantitative statistics have demonstrated the variations between study participants. These findings support the qualitative results in the next section as contextual background to the patients' lives.

5.3 Section 2: Contextual results of patients' lives and health-workers' work roles

This section is fundamental to understand the main analysis of results in Chapter 6.

Life situations of patients with chronic disease and pregnant women

A summary of contextual factors relating to patients' life situations including everyday activities, their experience of diagnosis and understanding of their health state and how they manage their condition are presented. The micro-themes reported in this chapter are connected to the use of digital technology for health discussed in the other results chapters.

Government social grants

Many patients were entitled to social grants, issued by the South African Social Security Agency.

‘I get a disabled grant for my chest and my heart failure but they sometimes cut the grant and I have to go to register again.’ (*Patient 2, female, 50-59*)

Employment and piecemeal work

Various descriptions of employment status included being employed by a company, another person or self-employed. None of the patients had full-time jobs away from the study site either because they had never been formally employed or were now too ill.

‘I don’t do much at home because if I work under the sun, I collapse because I have epilepsy.’ (*Patient 4, female, 40-49*)

A few patients were employed on short seasonal contracts by local farms, picking and packing fruit or clearing the rubbish from roadsides for the local municipality.

The majority of patients interviewed often had piecemeal jobs, running small businesses such as hair salons or market stalls. Subsistence farming was one of the most frequently referenced activities that provided an income.

‘I do go to the field and farm there; I harvest my peanuts.’ (*Patient 5, female, 50-59*)

‘Selling fruits, vegetables and Mopani worms at a market stall in Johannesburg.’ (*Patient 3, female, 50-59*)



Photo 13. Stallholder selling fruit at a study site village

Daily activities

Household chores and caregiving were common routine activities.

‘I am planting things in the field, fetching water, cleaning the house, sweeping the street.’ (*Patient 9, female, 25-29*)

A frequent initial response by patients was to report sitting at home all-day either chatting with others or using their phones. This matched the behaviour observed. Many were just sitting outside their homes on upturned beer bottle crates or mats on the floor, playing on their phones for entertainment.

‘I am not employed but when I am at home, I just sit with my phone chatting, open the Internet and stuff.’ (*Patient 11, female, 18-24*)

High school students in particular described how they exercise by playing sport or dancing.

Pregnancy amongst school-going women in the study site

South Africa has high rates of HIV, teenage and unintended pregnancies, high infant and maternal mortality rates and ‘mother-to child HIV transmission’ (Waldman & Stevens, 2015:6). A number of pregnant women interviewed were still attending school, although they were aged 18-years or over. Some women were in their final school year, Grade 12 and many were repeating their grade. This is not unusual as ‘in South Africa it is common that learners over the age of 18-years are still at secondary school because they can enrol late and repeat a school grade’ (Watkins *et al.*, 2014:113). There was a pattern that school-going pregnant women tend to go to their first antenatal care booking only in their third-trimester. This trend of delaying seeking pregnancy-care was attributed to not knowing that they were pregnant or feeling scared to go to the clinic. This corroborates with patients who leave it until they were very sick before utilising public healthcare and consider themselves as candidates of care.

‘I was very sick, bleeding a lot, only then I decided to come to the clinic and test. I find that I am HIV positive.’ (*Patient 14, female, 25-29*)

A recurring theme for younger women was being diagnosed with HIV during pregnancy.

‘I was pregnant when they diagnose me.’ (*Patient, female 18, 30-39*)

Patients' understanding and management of chronic disease

Patients discussed their lives before diagnosis and how they manage their chronic disease. This was important to understand where to consider where support may be required.

‘I had to stop working in the mines prematurely because of TB and then they found the HIV.’ (*Patient 10, male, 60-69*)

Patients explained their diagnosis was not easy to accept, often causing sustained worry.

‘My health is no longer that one that I know, since I am living with what is called high blood pressure and sugar diabetes.’ (*Patient 6, male, 50-59*)

Many patients took the day off work to attend the clinic every month. An epileptic patient described the period after he was diagnosed.

‘Eish! [*sign of expression in South Africa*] It is a long story... when it attacks me especially that sugar... without complying you will not survive, because sometimes you become dizzy and weak that you can't do nothing.’ (*Nkateko patient 6, male, 50-59*)

Another patient explained she stopped taking treatment when working away. It is important to recognise that people start to default if they run out of medication when away from home. They can not collect their regular treatment from the clinic until returning. Patients could not always remember how long they had been on treatment for over ten-years and taking medication had become routine. Often a patient's understanding of their disease was described in layman's terms.

‘I am taking the treatment for high blood because they said that my heart has a lot of oil and if I didn't take the treatment, my heart will beat very high.’ (*Patient 21, female, 60-69*)

Another patient said his life is more complicated now that he has hypertension.

‘The problem that I have is high blood. The way I used to be, it’s not the same; my body is complicated these days. They said I will take the treatment for the rest of my life.’ (*Nkateko patient 22, female, 30-39*)

Stress-factors such as bereavement were cited as causing a rise in blood pressure.

‘My high blood is better now but today its high, maybe it’s because one of my relatives passed away and I am not feeling good about it.’ (*Nkateko patient 20, female, 80-100*)

Eyesight as a factors related to the ability to use digital technology

An understated obstacle is the poor eyesight of many older patients. The provision of eye care is meagre in South Africa (Lecuona & Cook, 2011). Patients, who have had little or no support for their sight, reflected this. Many causes of poor eyesight were given. Often old age was the initiating factor for the deterioration of sight or the nature of a person’s work (mining or working in the sun), accidents or chronic related-symptoms (high blood or diabetes). This was a significant contextual finding because patients could not often see clearly enough to complete a task, such as reading. Poor eyesight has important implications for text-message reminder systems.

Eyesight problems

Patients described the eyesight problems and care they had received from either public or private providers. It was not expected that patients would readily discuss their poor eyesight as a major barrier to seeing text-messages or reading the Bible.

‘I do see a little bit but sometimes when I am reading, I will see the numbers as they have four lines. Sometimes they are aching. I don’t read, I just give my children to read it to me [*message on phone*].’ (*Patient 50, female, 18-24*)

‘My eyes are very poor, I cannot see clearly. I can see that there is something written on the screen [*phone*] but I don’t see anything.’ (*Patient 17, female, 70-79*)

There were a number of patients who had a visible cataract in one or both eyes and some with partial or complete blindness.

‘The right eye is blind at least the left one is better. Yes (*can see phone screen*) but only when it’s nearer, but when its far I cannot see anything. I was seeing an eye specialist and he told me it is because of high blood.’ (*Patient 11, female, 18-24*)

The hospital optometrist suggested that many patients came to the clinic because they were complaining they could not read or see their mobile phone screen.

‘You ask them “Why did you come for eye clinics, what is your problem?” generally they simply say “I cannot see my cell phone screen”. They want to put airtime, they want to phone relatives, so they need to see the numbers of the screen so they are phoning are the right person.’ (*Government optometrist 26*)

Eyesight referrals

Patients depicted the difficulty of getting a referral from the nurses to the hospital optometrist about their eyesight, often waiting years.

‘I once come here at the clinic and they told me to wait for a doctor but since then the doctor never come.’ (*Patient 28, female, 50-59*)

The affordability of glasses through the public health system is not an option for many. Although glasses are heavily subsidised by the DOH, patients still need to make a monetary contribution.

‘I did see the doctor and they wanted money for the glasses then I didn’t have it [money].’ (*Patient 25, female, 60-69*)

The optometrist said that the cheapest glasses with basic frames and lenses would cost R50 and take five weeks.

‘It is not really free because they have to open a file and they pay an amount at the clerks office [R10-20] depending on where they work and how much they earn.’ (*Government optometrist 26, female*)

Some people had the opportunity of going to the annual healthcare train. The train is a parastatal partnership sponsored by medical funders, to provide care, such as eye and dental clinics. Patients’ queue over-night outside the train, that provides free health services for two weeks. Patients could pay R5 for a pair of glasses, custom made on board the train.

Other patients had seen a private optometrist and were wearing glasses paid for by a family member’s medical-aid scheme or as an out-of-pocket cash payment.

‘Eye test is R300 and if maybe they need spectacles it depends on the lenses and frames. But it is cheaper of course [*at the hospital*].’ (*Government optometrist 26, female*)

Section 2 has given an overview of the types of chronic patients and pregnant women interviewed. A focus on income and eyesight, which may directly affect a person’s ability to use digital health solutions, was explored. Similar contextual life situation examples are presented in Appendix 9. A.

5.4 Section 3: Contextual findings of the South African public healthcare system as general context to the Vutivi study

The next description of micro-themes is based around the South African health service's delivery structure. This is necessary to comprehend where digital communication is evident or could be used, given the current clinical environment. To appreciate how rural clinics and hospitals function, the structure of typical appointments, the role of nurses and doctors and the types of patients accessing care is described. This section gives supportive background to Research Questions 2 and 3 in the next chapter.

Clinic context

Nurses' work role

Rural clinic nurses have to run many different health programmes to cope with the quantity and variety of patients needs.

‘We are doing the clerical work, we file, we open files, we screen and we dispense, we don't have a pharmacist. We do everything.’ (*Nurse 73, female*)

‘The chronic care model says by 11am, we should be finished with the chronic. People are people. But it doesn't work like this.’ (*Nurse 74, female*)

Nurses' explained that they are constantly multitasking.

‘Normally you find that you are working on five things at the same time and you are one.’ (*Nurse 75, female*)

Often they cannot work overtime because they rely on public transport.

‘I stay at Town X because the taxi end around 6 o'clock, afterwards you don't get one and I don't have a car.’ (*Nurse 76, female*)

Nurse administration and paper work

Nurses' manually record data.

‘There is nothing we can do without the pen, if you do something and you don’t record it is zero, you haven’t done anything in nursing.’ (*Nurse 75, female*)

The nurse laughed at the size of the books used for registries.

‘It can not fit anywhere! When you open it, it fills up the whole table. I do work at Orthopaedic wards. They only have some admission books, statistics and some dressing books.’ (*Nurse 81, female*)

Patient capacity and staff shortage

Staff to patient ratios are poor and the nurses addressed this as an ever-present problem.

This is in accordance with the literature in Chapter 2.

‘There is no-way we can minimise the number of clients. We can not say don’t come to us as there is no nurses, that is none of their problem. They should get more nurses. Now overstaff against the number of clients.’ (*Nurse 78, female*)

Staff shortages require them to be resourceful.

‘If we had a clerk who was working during the night the queue would be running faster. They [*the patients*] get stuck there. They have to wait for the clerk... around 8am.’ (*Nurse 79, female*)

General clinic environment

The clinic environment was exposed through direct observation and interviews with healthcare staff in rural clinics. This was necessary to understand where digital technology is already in use or could be in the future.

Typical appointment day

Patients arrive from 5am and are given a number card by the clinic security guards; they then wait in the inside or outside queue. Patient files are then collected. The monitoring of vital signs including blood pressure and weight measurements, are routine for all patients attending the clinic. The nurses suggested that patients should self-monitor at home and then send in the readings, which should speed up the vital sign queue.

Duration of patient consultation and prescribing of medication

The length of time a consultation takes is dependent on factors such as the type of conditions the patient presents. The nurse described the ease of a patient who just comes to collect the treatment and has no other ailments.

‘It’s fast but it is when they are collecting treatment but also have other ailments it slows everything down and this is common.’ (*Nurse 75, female*)

In some clinics, patients were asked to bring any remaining tablets they had from the previous month. This was to enable the nurses to see how well the patient was managing to remember to take their treatment.

‘Yes, they do count them (*the remaining tablets*) and when I come, I come with the left over medication then they count and write it down; after that they will

give you other tablets to add. They give us maybe tablets for one month or two months.’ (*Patient 29, female, 30-39*)

The patients appreciated this system.

‘It is good because they want to know if you don’t miss your tablets on some of the days. When they have counted it they know that when you come for your appointment you will come with how many tablets.’ (*Patient 84, male, 40-49*)

The next section describes the different sources of health education that patients can access.

Patient health education from health facilities

Patients gained most of their health education and understanding of chronic disease and pregnancy advice from the clinic nurses. Figure 21 summarises other sources of health information.

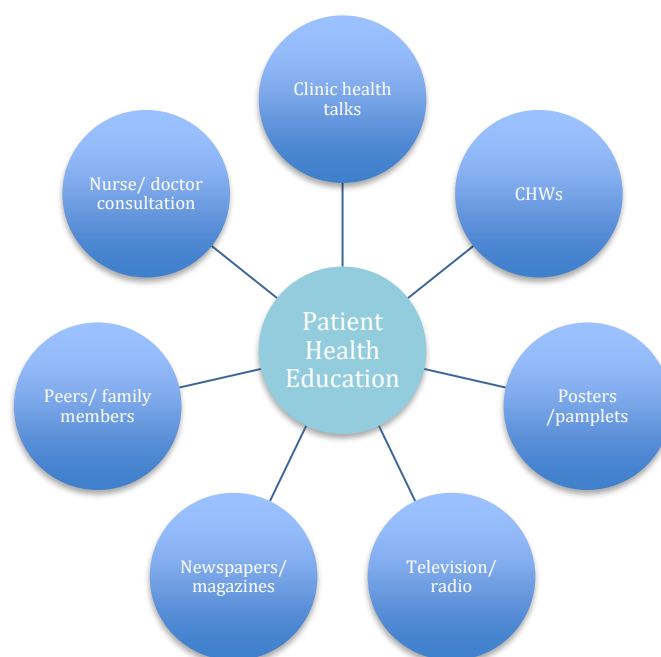


Figure 21. Diagram to illustrate the different sources that patients can gain health information from

Advice from nurses during the consultation

Pregnant woman explained why they do not always ask the nurses' questions.

‘It’s not easy because when she is in the consultation room and you get there you find that she is tired because she was working since morning. When you ask her questions, she ignores you.’ (*Pregnant woman 39, 30-39*)

The patients described examples of what nurses had taught them to help manage their chronic disease effectively or what to experience during pregnancy.

‘To use the treatment well, is just to follow the instruction from the nurses. They are telling us to use the treatment every day and how many in a day.’ (*Patient 94, male, 60-69*)

Morning health talks

Every morning, the nurses present a non-compulsory health talk, for patients waiting in the queue.

‘In the morning they come teach in general, then teach hypertension to everyone and then one-on-one when you come into my cubical then you will explain.’ (*Nurse 95, female*)

The nurses explained that they also try to teach patients about any unfounded myths that patients believe in. For example, Western and local names of diseases such as Mafularha (the name given by Shangaan people for symptoms similar to TB).

‘It is TB but the patient did not understand Mafularha is TB. They think they can take herbal medication for Mafularha and then for TB take clinic medication. But it is one in the same. Mafularha is TB. We explain to them thoroughly so they understand.’ (*Nurse 71, female*)

Patient health education from alternative sources

It was difficult to ascertain what the most effective information source was, as it was often person-dependent in terms of age, gender, educational status, socio-economic status and technology exposure. Accessing health information from sources other than clinic nurses was essential because often patients had a poor understanding of chronic care.

‘I have learnt it once in the clinic where they teaching about how to take your treatment, but since then I never learn anything about high blood.’ (*Patient 17, female, 70-79*)

It was important to understand where people were getting health information from currently to see whether this could be adapted and delivered to use mobile digital communication. Patients are seeking information from a little bit of everywhere and a lot of nowhere suggesting access to health information was fairly sporadic and minimal.

Education from the doctors

The doctors clarified that it was the responsibility of the nurses to teach patients at the primary care level but they are often under-staffed.

‘They are not able to get down to the nitty-gritty of primary healthcare intervention. I still speak to diabetic patients and ask them what they think about correct and incorrect foods and they don’t understand.’ (*Doctor 70, male*)

Doctors’ elucidated that they try to give dietary advice and the basics of health during outpatient consultations, often translated by a sit-in nurse. They did not know how accurate the nurses’ translation was or if the patient really understood.

‘You do that a little bit to teach them the basics and get dietary advice, translated into Shangaan. In the clinics, the nurses should be doing talks, but what happens is they get prescribed the medication and they do not get a whole lot of help.’

(Doctor 63, female)

It was evident that even the doctors had little understanding of where patients gain health knowledge.

‘Maybe on the radio. There are no great public health campaigns in this country; I was really shocked when I got here. Sometimes for HIV but barely anything in the media. The government has put lots into treatment side which is working but nothing into prevention.’ *(Doctor 63, female)*

Another rural doctor said the local radio hosts a regular health programme and often the junior medics doing a public health module are encouraged to speak on air.

Health education from the community health-workers (CHWs)

The strengthening of primary care through CHWs can reduce costs by providing preventive care and education, delivering interventions and cost-effectively managing chronic diseases. CHW are called home-based carers within the study site. They are volunteers with no payment from the government or NGOs. Part of their duty of care is to educate patients at their households. A home-based carer described their work role.

‘Clean, assist with taking treatment, if the patient is unable to do everything they even cook for them.’ *(Home-based carer 152, female)*

Community awareness days

A doctor clarified that the budget for health promotion in the province was very small, so public health awareness campaigns are rare.

‘Sometimes they would have an awareness day [*in the community*]. I know in Mpumalanga the health promotion budget was like R100,000 for the whole year. So that maybe just answered your questions.’ (*Doctor 62, female*)

Alternative sources of patient education were varied as illustrated in Table 24. This was important in order to determine where digital health information could play a role.

Table 24. Sources of patient education and explanation from the participants

Source of patient health education	Explanation and evidence from Vutivi study
Family members and friends	<p>Many patients cited family members as being an important source of information. One patient described a group of women who came together and taught about pregnancy-related issues.</p> <p>‘I have learned here at the clinic because they normally teach us how to take care of your pregnancy and also from other moms at home; they do come and teach you how to take care of your pregnancy.’ (<i>Pregnant woman 38, 18-24</i>)</p> <p>One pregnant adolescent suggested that her mother gave her colloquial knowledge such as not eating ice-lollies but fruit instead.</p> <p>‘I ask her (mother) about how the baby kicks. She also told me that I have to stop eating ice cubes because I will feel cold when I’m in labour.’ (<i>Pregnant woman 130, 18-24</i>)</p> <p>‘I usually ask my aunt the questions because those I am staying with I am afraid of them but to my aunt I am free. She told me that the vagina do stretch like a Chappies (<i>chewing gum</i>) and then the child will go out easily.’ (<i>Pregnant woman 13, 18-24</i>)</p> <p>Some of the chronic patients said they discussed their diet with friends who also had high blood pressure.</p> <p>‘With friends we do talk about high blood, like I will say today I am not feeling well because of the high blood. Then the other friend will ask if you haven’t eaten mango as now we have lot of mangos and pawpaw (<i>papaya fruit</i>). When you have eaten such things you will feel that your BP is not ok.’ (<i>Patient 37, female, 60-69</i>)</p>
Peers	<p>Often people have a social network of friends in their community who are their peers and whom they can ask questions about health. This lay knowledge is an important part of many patients understanding. Speaking to peers or other patients in the queue about health was a recurrent topic.</p> <p>‘As we are all pregnant in the same queue, so we talk about pregnancy; each one will say what is happening to her.’ (<i>Pregnant woman 145, 40-49</i>)</p> <p>‘I do tell my friends that today I am going to the clinic to be collected blood or I am going to collect my treatment.’ (<i>Patient 15, female, 30-39</i>)</p>
Newspapers and magazines	<p>It was rare for people to say they bought and read newspapers. Those who did described the health-related articles as an occasional useful resource.</p>

	<p>‘I read <i>Sowetan and Daily Sun (local newspapers)</i>. I like it a lot because I find things that are very interesting. Sometimes a person talks about how she gets infected with HIV and how is she getting help and I too get help from that story.’ (<i>Patient 57, female, 30-39</i>)</p> <p>One patient said she used newspaper articles to explain to a friend about HIV, but she did not listen and actually died because she refused to accept her status. She read the <i>Move</i> magazine every Thursday for R8.50 in English. The articles were about her illness and she felt she could relate to them.</p> <p>‘Sometimes there are those who have problems and they write to <i>Sister Dolly</i> and <i>Doctor Steve</i>, I read about those because sometimes I can relate them.’ (<i>Pregnant woman 54, 18-24</i>)</p>
Television and radio	<p>It was very common for people to own a television. Televisions have become a commodity that most households have even at the poorest quintile of status. Some women get pregnancy information from television programmes.</p> <p>‘<i>Siyanqoba</i>, on <i>Shift</i> they talk about pregnancy sometimes. They do talk about teenage pregnancy, pregnancy and different thing that are happening in the world.’ (<i>Pregnant woman 43, 30-39</i>)</p> <p>Another participant watched television programmes related to health and learnt about other people’s health in relation to her own.</p> <p>‘I was watching SABC 2 (<i>South African Broadcasting Corporation channel</i>) and they were talking about itches and there were people who are HIV positive and they were saying that HIV doesn’t have stigma.’ (<i>Pregnant woman 54, 18-24</i>)</p> <p>The opportunity for patients to listen to health talks on the radio was evident. It was usually a chance ‘education’ because the programme happened to be on when the patient was listening to the radio.</p> <p>‘I have listen to the radio where they teaching about high blood and they were saying that we mustn’t eat food with oil, we mustn’t stay angry but we have to be happy all time.’ (<i>Patient 25, female, 60-69</i>)</p> <p>Another women said she learnt a lot from the radio on her phone.</p> <p>‘There are lot of things that they are teaching on the radio; things like how to feed the baby. And what kind of lunch box does the child have to carry.’ (<i>Pregnant woman 48, 25-29</i>)</p>
Pamphlets and posters	<p>There was a mixed view on whether clinics had information pamphlets from the district DOH for the patients to take home with them. It is unknown why some clinics had better health information resources than others. Some of the time the nurses explained they were out-of-stock and that nobody from the department had sent more.</p> <p>‘Here at the clinic they don’t have the pamphlets to give us to take home so that we can read.’ (<i>Pregnant woman 54, 18-24</i>)</p> <p>The patients said taking the health information home was important, in addition the verbal advice. It meant that in their own time they could read the information. However, patients admitted to not reading the pamphlets at home.</p>

	<p>‘I once taken it at the hospital and I told myself that I am going to read but I didn’t read it; when you are at home you have a lot to do, so I end up not reading it.’ (<i>Patient 85, female, 30-39</i>)</p> <p>Patients who were literate enjoyed reading the posters on clinic walls because it increased their health awareness. The nurse referred to the posters as useful for both patients and the nurses (as decision-support tools or algorithm reminders) because they were displayed in the waiting areas and in the consulting rooms. However from observations, it was apparent that many of the posters were very out-of-date. Not all patients could read the text on the posters but they could look at the images and pictures, which were usually very visual without needing words to support their meaning.</p> <p>‘Some of them I do look at it and read but you find that some English words on the posters I don’t know them.’ (<i>Patient 18, female, 30-39</i>)</p>
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District hospital context and description of facility challenges

Following on from a description around the clinic environment and patient health education, the next section describes the district hospital environment and challenges that persist in both clinic and hospital settings.

Doctors' work role

This section describes the job roles of health-workers in the rural district hospital.

Government employed doctors

The majority of junior and senior doctors in district hospitals were generalists, working in all wards and on rotation rather than specialising. Some of the more experienced doctors, such as an orthopaedic surgeon, worked with the junior doctors to pass on their skills. Two doctors said they also did voluntary outreach in local rural clinics. The provincial government supported this scheme until costs were cut and reimbursement of fuel expenses curtailed. Despite this, one doctor used her own vehicle and fuel to transport a nutritionist and optometrist to the clinics, so outreach services could continue.

Private doctors

Three of the doctors had their own private general practices in nearby towns but still worked part-time for the government hospital.

Types of patients using the public health facilities

The doctors described the different types of patients they encounter as undifferentiated patients.

‘A good or bad doctor, will decide where they will go, help them there or refer them on. You can see a whole variety of patients, you have to use whatever skills you have or think you have, to help them out.’

(Doctor 125, male)

The LHW explained that it is the men who often ‘present late’ to the clinic.

‘Most of the men, they don’t like to come to the clinic. They don’t want to check, they just want to live. They don’t want to know their status.’ *(Lay health-worker, 155, female)*

This presents major challenges for the clinics because they are continually dealing with preventable illnesses. Several doctors believed there is a shortage of public health campaigns to educate the patients.

‘The government has put lots into treatment side which is working but nothing into prevention.’ *(Doctor 63, female)*

One doctor crudely discussed the lack of patient education, particularly in the rural areas. He believed that the reasons for patients presenting late is linked to a lack of education or unwillingness to accept illness. He advocated public health education because it helps with prevention in the first place. He said patients are very uneducated and because of that they deflect the health

system. This is often because they have sought an alternative source of healthcare before utilising the care at the clinic or hospital.

‘I enjoy public health, everything can be prevented... the biggest problem of public health is education in this area. That is the biggest one. Because patients are uneducated or partially educated they either present late or don’t present at all. Or they present to another source of healthcare prior to coming here. So if they do that or they present late, by the time they get here, it becomes a palliative service.’ (*Doctor 125, male*)

A doctor explained that migrants return home after being diagnosed if they are very sick. This phenomenon has been termed ‘coming home to die’ (Clark *et al.*, 2007).

‘Traditionally it is the men, migrants who come back from Joburg, come home to die. People still bury their head in the sand, I still say to the patients ‘have you tested?’ and there will still be some that will say ‘yes’ or ‘no’.’ (*Doctor 63, female*)

Hospital doctors said they routinely see neglected cases of HIV patients with TB describing it as an endless repetitive cycle due to disconnect between government departments. A doctor said he treats the symptoms rather than the causes.

‘Not treating the causes, your job just becomes a monotonous thing of seeing mismanagement through the system where ever you go, public

health, Department of Health, Department of Education, Department of Agriculture, department of anything. The departments all have to be integrated in some way much more than they are.’ (*Doctor 125, male*)

He described the public health vicious cycle of treating one case after the other.

‘So even if it is not HIV and it is just malnutrition and TB, wicked combination, treat the TB get the child better, I discharge that child and five minutes later an identical child walked in. There is obviously a public health problem.’ (*Doctor 125, male*)

He also said this would only be reconciled once ‘you sort out your basic public health principles of education, food, water... you then can’t solve your other problems.’ Another doctor described how many patients do not really understand the treatment regimen they are on.

‘Often patients do not know what medication they are on. Often they are on poly-pharmacy [*multi drugs*].’ (*Doctor 67, male*)

The doctor explained that the number of patients meant that the doctors are ‘not really seeing patients properly, literally running through patients’ (*Doctor 67, male*). Patients just accept the system and do not blame the doctors about the situation.

‘For us it is frustrating to see that these poor patients are lying there and there is not really any real help for them... The patients seem to

accept that it is not our fault and there is nothing we can do about it personally, they don't seem to blame us. I must admit that many people are very stoical and they seem to accept that that is the situation and nothing can be done about it.' (*Doctor 146, male*)

Another doctor explained how sometimes the nursing is poor.

'You might have spent a lot of time and effort operating on a patient only to find the next day they have not been nursed correctly in the night and the results might not be as good as you would like them to be.' (*Doctor 146, male*)

The same doctor's view of primary healthcare was 'It's pathetic, there is no commitment'. He believed that even though many patients are in the system for a condition they have had for years which is well-managed, other conditions may be undiagnosed. Frustrations of working in a government hospital were varied. One doctor said he had learnt to not let it distress him, otherwise he would not get anything done.

'There are many frustrations and if one is going to work in a government hospital you have to learn to not let them worry too much. If you are too concerned about perfection, you will become a bundle of nerves and you will not survive.' (*Doctor 89, male*)

5.5 Rural health system challenges in clinics and hospitals

A host of other health system challenges need to be considered when thinking about future digital health implementation in this context.

Hospital processes and antagonisms

From the interviews with health-workers, patients and hospital administration it was apparent that there are a multitude of challenges and barriers within health facilities. These are described through several hospital processes, also evident in clinics. Health facility procedures and associated problems are described.

Hospital outpatient department and the clinic queue

The outpatient department, according to one doctor, is plagued by the slow start in the mornings, caused by problems of accessing patient files. Patients queue together awaiting their files and for vital signs to be checked before seeing a doctor. The long waiting times define the primary health and outpatient systems. The government has taken action in trying to coordinate the queues by separating different patient groups from one-another and scheduling appointment dates. However, there is still patient and nurse antagonism about the length of the queues.

Reasons for slow clinic queues

One patient blamed the slow moving queue on the speed of the nurses.

‘Honestly, it takes a long time; we are just sitting, thinking, being lazy and thinking about my labour. We even get hungry.’ (*Pregnant woman 43, 30-39*)

The nurses put the queue down to the sheer number of patients.

‘A lot of people are coming here to consult, that is why I come so early.’ (*Patient 16, female, 60-69*)

Some patients described the experience of sitting and waiting for many hours as painful because they were sick and often have not eaten, especially if fasting.

‘Sometimes I am sweating while sitting and have aching bones and the sores on my hands, I have told them here at the clinic but I am not getting help.’ (*Patient 50, female, 18-24*)

Doctors’ opinions about the hospital queue

A bottleneck occurs if the patients arrive at the same time. One doctor explained how she tried to manage the queue to speed it up.

‘There is a queue marshal to make sure people don’t jump and responsibility that the person outside the room has got their notes and previous blood tests.’ (*Doctor 70, male*)

Other doctors preferred not to take on managing the queue because patients think they are treating others more fairly. However the doctor thought it

would be better if the clinical associates could filter the queue by making clinical decisions about where patients should go next.

Patients do not tend to complain because they are stoical and are just grateful for the health service provided.

‘They just sit. That is a result of apartheid. They have been taught and trained that is what you do, you don’t complain, you are grateful for what you get.’ (*Doctor 63, female*)

The provincial policy-maker said the queues were long because of shortages of staff.

‘Long lines with few personnel to service them and a habit of [*patients*] seeking treatment from the hospitals and bypassing local clinics. Patients want to be consulted by doctors always, irrespective of the condition.’ (*Provincial policy-maker 101, male*)

Other hospital processes that slow the start of consultations are due to the retrieval of patient files.

Patient file retrieval

The clinics and hospital patient file retrieval systems are linked to the speed of the queue. This in turn slows down the patient pathway, delaying care. A description of the paper patient files is in Appendix 13 and Photo 14.



Photo 14. Storage of patient files at a primary healthcare clinic

A doctor recommended that an improved and safer filing system is warranted.

‘The reason for that is the poor filing system at the moment, and there are three sites where the records are kept and it is not alphabetically.

I don’t quite understand the system.’ (*Doctor 70, male*)

The doctors had tried to change the system but ‘it never gets resolved... we have had meetings with the clinical manager and officers in the clerk’s office’ (*Doctor 156, male*). The private doctor who also works at the government hospital said that by the time her shift had finished, she had barely seen any patients because they were still waiting to receive their files. There are three houses the records are kept in and ‘a quasi reliable hospital database’ (*Doctor*

156, male) but this is only for maternity and HIV records. There was a reoccurrence of files being lost.

Patient referral process

A major problem with patient care is the process of referrals.

Transport issues

Patients who need to be transferred from the district hospital to a tertiary hospital are transported by hospital transport, consisting of non-emergency vehicles and emergency vehicles.

‘The patients have to be referred to see specialists who also have greater resources such as specialised equipment such as anaesthetist, surgical, orthopaedic.’ (Doctor 67, male)

However, the doctors explained that often the vehicles were not working and not everyone could afford public transport to travel far distances.

‘For the past two months, both of those combis (*mini bus*) have pretty much died and we are unable to take the patients... those who have money to get onto a taxi, they can go, but everyone else it is not happening, which is discriminatory those who have the financial means to afford the cost of public transport to the nearest hospital and those who cant there is no other option. This is a case of poor maintenance strategy and human oversight.’ (Doctor 67, male)

The same doctor argued that the situation is symptomatic of the ‘poor maintenance strategy and human oversight’, blaming hospital management for avoidable problems. The more socioeconomically deprived suffer as a result because the health system is not able to support them. Affordability of transport is a severe problem and daily hindrance to both the patients trying to receive care and doctors trying to coordinate the care. The vehicles are not well maintained and are driven long distances. The blockage in the referral system is caused by inadequate transport.

Emergency services (EMS)

When the doctor phones the operator they do not even know when the EMS vehicle will arrive. The vehicles struggle to get to the clinic because of the poor roads.

‘Yesterday we called EMS. They arrived here passed three so it is a very serious challenge that one.’ (*Nurse 90, female*)

When the hospital does not have any working outpatient vehicles, EMS has to be used. A doctor emotionally described a recent incident where the transport situation failed him and the critical patient passed away before the EMS arrived.

‘No, referring patients is a difficult thing. It did not arrive on time and we actually lost her.’ (*Doctor 67, male*)

The doctor emphasised the ‘fuss’ other doctors and him had made about the debilitating situation but nothing had been resolved nor would it likely to be.

‘I feel like they are not ignoring it I feel like the barriers are bigger than someone in that office.’ (*Doctor 146, male*)

Coordination of care

Weaknesses in the referral system are often caused by the poor transport system. One of the long-standing health system challenges is the referral pathway with patients overcrowding facilities, often far from their own areas (Naidoo, 2012). The first being stagnant referrals that lead to often failed referrals. The impetus to organise a referral exists but the ability to create a successful referral is hampered by a number of hurdles, which cause either delays, or halt access to care completely. For example, when the district hospital did not have the specialists required for higher-level care or equipment, a referral was necessary to a tertiary hospital. This can lay stagnated, preventing the patient from accessing the next stage of treatment. Therefore once a patient has broken into the system, this does not mean they are then on an upward trend to continued-care.

The current referral process within this rural province involves the district doctor phoning on a fixed-line phone to the tertiary hospital via a switchboard, which can be slow and sometimes never answered, as well as providing a hand written letter. Occasionally a fax is sent, if prearranged so

they can triage the referrals at a convenient time. Transfers can be a long and arduous process for doctors.

‘That process in itself can take long just sitting on the phone and speaking to the person.’ (*Doctor 146, male*)

Clinics cannot refer the patient directly to a specialist. They still have to go through an outpatient doctor before a referral can commence. The referral system has been described as a bottleneck because there is no infrastructure to support it.

Referral letters

When a patient has been referred from the clinic to the district hospital, doctors rely on the referral letters for the patient information. Doctors have minimal information about the patient from the clinic except the referral letter written by a nurse.

‘So you have no idea whether they got the treatment they were supposed to, or maybe the treatment was out of stock that’s why they were talkative [*referring to a patient with a mental condition*].’
(*Doctor 62, female*)

The doctor showed a discharge letter in a patient file that she had received (Photo 13). It had been written by a nurse and was almost impossible to decipher. The doctor was illustrating the problems she had in understanding a patient’s case, if the notes are illegible (Photo 15).

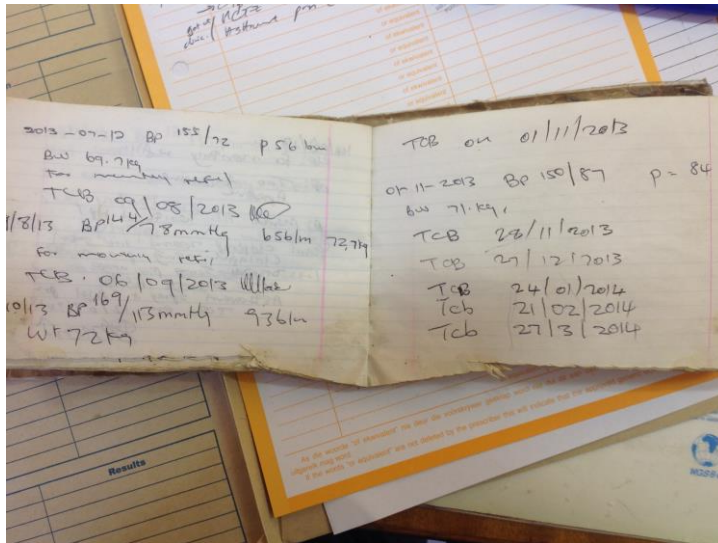


Photo 15. Image of a hand-written patient file

Equipment issues

Clinic and hospital equipment issues were explored because this was an important part of understanding how in the future digital communication systems would be maintained. This current situation can indicate future issues, management and maintenance strategies. Naidoo (2012:149) explained the lack of or poorly maintained medical equipment must be addressed ‘by improving the supply chain management systems with competent managers in all provinces’.

Lack of facilities and shortage of equipment

Clinic nurses suggested there was a shortage of blood pressure monitors. A doctor described that new equipment is easily damaged or stolen, and often never replaced.

‘Ten years ago we had a digital X-ray facility here so all X-rays went digital screens in each department. My understanding is before I came here it got scrapped; cables and screens went missing after two weeks. There are real problems of roll-out of expensive technology in rural areas.’ (*Doctor 70, male*)

At the time of interview, there was no functioning X-ray machine in the hospital. The doctor said they had been waiting for over two-years for a working ECG machine.

‘We are on the seventh submission to the DOH with no return. So now I have seen no evidence of a maintenance repair policy.’ (*Doctor 70, male*)

Hospital maintenance strategy

The current maintenance strategies in the clinics and hospital are a fair representation of possible future issues with digital technology. The hospital manager said that the re-ordering of hospital equipment was dependent on the urgency of need.

‘If very urgent we short-circuit other things, equipment often on tender. The section head is responsible for putting in a request for the specification of what they want and this goes through the financial supply chain depending on how much it is worth, there are lots of processes for getting quotes.’ (*Hospital manager 65, female*)

The doctors suggested that there was no hospital maintenance strategy in place for when equipment broke down.

‘It just requires someone to manage it, but no one is actually doing that... I think in the casualty it is not, it looks a dump. But in theatre there is a mix of old and new. A lot of the equipment is old and run down or they buy new equipment which is not maintained and two years later it breaks and no one knows how to fix it.’ (*Doctor 63, female*)

One doctor believed that equipment was not repaired because of the financial burden. She thought this was short-sighted as there should be better prioritisation of purchasing of new equipment.

‘To no avail, little fruition, seventh submission to DOH for ECG machine.’ (*Doctor 70, male*)

Many of the issues about defective equipment are around mismanagement, discussed in Chapter 8. Another poorly managed system is the drug re-ordering system.

Pharmaceutical availability

One of the major problems that health-workers and pharmacists discussed, is the inconsistent and interrupted pharmaceutical drug supplies in the health facilities.



Photo 16. Example of drugs stored at the clinic pharmacy

Clinic drug shortages and sharing of drugs between clinics

Medicines that were out-of-stock ranged from treatment for minor ailments to long-term chronic tablets.

‘Cough mixture, calcium gluconate, not there for 4-months, treatment giving us a problem, out of stock takes a long time to come back again.’ (*Nurse 68, female*)

There seemed to be some medication sharing between clinics when one was under-stocked. This system is informal and relies on the initiative of the

nurses to phone around nearby clinics. Often the courier who collected the blood samples was given the medication to take to the next clinic. He was doing the nurses a favour and was not employed by the government.

Hospital drug shortages

The doctors were given notice about what drugs were out-of-stock each week, so at least they could prescribe an alternative.

‘They [*hospital pharmacy*] send us a weekly newsletter of what is out of stock every Monday. We get a list of what is out of stock that week.’ (*Doctor 70, male*)

There were times when the doctor prescribed medication that the pharmacy had ran out of.

‘By the time they [*patient*] comes back for check-up, you realise that nothing has changed because they didn’t get the right medication that they were supposed to get and so it is a challenge.’ (*Doctor 64, female*)

A doctor described recent stock-outs he had encountered, ‘We do run out of Panado [*brand of paracetamol*] the common things, ibuprofen and even some of the big guys’ (*Doctor 67, male*), referring to antibiotics.

Reasons for shortage of stock at health facilities

There were different opinions on why drug shortages at the hospital level occurred. Doctors' believed drug shortages were caused by a lack of communication.

'It is very true we have a huge problem with shortage. It is not shortage because we don't have the money, it is shortage because the person who is meant to be ordering does not order on time so that there is that gap and there is a poor communication between the user and the orderer... there is not good communication.' (*Doctor 67, male*)

Some of the nurses thought the 'drugs are running short because of the number of patients we are having' (*Nurse 69, female*).

Sometimes the nurses had no option but to change the patient's treatment depending on availability.

The nurses recognised that the current system of hand-writing faxes to reorder drugs from the depot, was in need of an update.

'Take to dispensary at Hospital X. Comes each week. We run out of drugs they take the order form and then drugs are running short because of the number of patients we are having.' (*Nurse 69, female*)

A private pharmacist explained that many patients are reluctant to go back to the hospital for their medication because of the queue and choose to pay.

‘It’s very affordable... they might as well get it from us and forget about the hospital... it is basically the queue and the treatment at the hospitals the way they are treated by nurses, the government hospitals is not really the place you want to be.’ (*Private pharmacist 140, female*)

Some of the patients used their social grants or income to buy the medication. A doctor said that the hospital and clinic pharmacies are always out-of-stock and gave her view on why this was the case.

‘Always running out, it is a whole process there is so much bureaucracy and corruption.’ (*Private pharmacist 140, female*)

There was an example of equipment malfunction. The pharmacy ran out of ink for their printer so they stopped ordering medication because they could not print the forms. Often the doctors knew where the start of the problem lies but have no authority, time or energy to deal with it because they are just trying to fulfil their duty of care. One of the pharmacists cynically said the drug ordering system is poor because the whole process is bureaucratic and corrupt.

Government pharmacy's ordering system

The pharmacists said the ordering system used be done via email but collapsed probably because of cost issues. The nurses used to scan the barcode of the required drugs.

‘We write on the form, but before, when we were under Limpopo Province, we used to do the scanning, and then they come and withdraw the information from the scan. Actually it’s almost going backward, because you used to have that technology.’ (*Government pharmacist 157, male*)

Drug stock-outs are further explored as a major theme in Chapter 6.

Additional external issues that create challenges to the public health system

Infrastructure issues

Infrastructure issues were highly cited amongst health-workers and are acknowledged by the provincial DOH.

‘Our infrastructure, that is a huge problem our buildings are old they are dilapidated also do not meet the standards.’ (*Provincial policy-maker 118, female*)

Doctors complained about the poor phone signal inside and outside of the hospital. The hospital is on the outskirts of a small town and there is a large mast nearby but this only serviced one mobile network. One doctor had

started lobbying to the major network providers about the how the issues of poor signal affect his work in a rural hospital. He had set up Google Forum survey for other rural doctors to voice their mobile network problems.

‘It is a common knowledge that Internet via MTN is only possible at midnight, while other networks are just a disaster. Network coverage blackout is a common occurrence and any attempt to address this has failed.’ (*Doctor 61, male*)

A press statement by the Rural Doctors Association in November 2015, called for improved cellular network coverage over rural health facilities.

Facility management issues

Many of the contextual examples described were issues of inadequate management. For example, poor referrals were also a sign of mismanagement of resources and poor allocation of funds.

‘There are a lot of the acting, acting phenomena. We have “an acting acting clinical manager” who is in charge. They take over a poorly performing hospital and then exit as quickly as possible and I don’t always blame the person. This means it is difficult to build sustainable trusting relationships. It does mean that the prospect of it improving is challenging.’ (*Doctor 70, male*)

This doctor thought that many of the problems could be attributed to the way those in positions of power (hospital management) do not stay in the post for

long, making it difficult to build sustainable trusting relationships ‘with someone upstream’. (*Doctor 70, male*). A junior doctor doing his community service elective in the rural areas said his reasons for not wanting to continue working in the rural hospital long-term was because of ‘very frustrating dysfunctional management’ (*Doctor 125, male*). Clinical leadership and medical engagement were also failing.

‘We have no shortage of money, we have no shortage of infrastructure and we have no shortage of people. What we do have a shortage of is the efficiency by which we can use all of that and the management construct to be able to carry out those functions.’ (*Doctor 6, male*)

The doctor argued that the continuity of senior management staff was a major issue because it is so poor that it impacts on the ability for hospitals to overcome the challenges they face. The state of the health system is a result of no commitment and ‘un-kept promises harvested over the years’. The same doctor said the mismanagement issues were in fact through all government departments, not just health.

‘Constantly seeing mismanagement through the system where ever you go, public health, department of health.’ (*Doctor 125, male*)

A doctor bluntly and realistically said that nothing would improve unless the management does because change has to come from the top.

‘I would say it is the whole system but it starts out with the management and if your management sets a certain example then

everyone only expects a certain level of service down there.’ (*Doctor 70, male*)

More responsibility and accountability to hospital and district managers is a critical mechanism for improvement. The development of ‘executive leadership and management training programmes’ is necessary to develop innovative change agents to support the transformation of the health system (Naidoo, 2012:3).

Summary of the health system challenges

Hospital processes such as the queue, file retrieval, referrals and drug stock levels all have antipathies. Perceived challenges by health-workers have been explored to discern how best digital communication systems can support some of these challenges. The description of management issues is a useful indicator for possible problems that may arise when more formal digital systems are in place. However it also raises areas where digital communication may act as a supportive solution. Although some doctors thought eHealth and mHealth would be just the ‘tip of the iceberg’ and have no impact or ability to impact some of the ingrained challenges that the health system faces.

5.6 Conclusion of Chapter 5

This chapter has highlighted three distinct sections to contextualise the findings in the next chapters.

The study sample accurately represented the study site population. HIV and hypertension are the most common chronic diseases of patients' interviewed. Patients earn money in a number of ways that can be formal or informal. Daily activities were varied but often revolved around farming and cleaning as everyday chores. Poor eyesight was a reoccurring micro-theme that can affect everyday processes, such as using a mobile phone. The descriptions of the healthcare settings described the process patients go through on an average clinic appointment day. Patients learn about health predominately from their clinic but there are other sources of information such as posters and the radio.

The hospital environment is besieged by many challenges that affect the daily functioning of the health-workers, such as stagnant referrals and poor drug availability. Often causes of these challenges are the infrastructure or management problems. Contextual findings are an integral part of supporting the main themes and will be explored in relation to the middle-range theories to follow.

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Chapter 6 presents key themes, in relation to results from the realist review.

Chapter 6



Photo 17. Airtime for sale outside a community member's house in the study site

Chapter 6: Results – How patients and health-workers are using phones and computers in relation to health

6.1 Overview of Chapter 6

The broad context of patients' lives and clinical environments has been discussed to support the main themes presented in this chapter. These findings from the field site are in relation to Research Questions 2 and 3: *the current and potential use of mobile phones and computers to enhance the delivery of healthcare.*

Linking the realist review to the empirical results

The realist methodology will be extended in the qualitative results by using the Context-Mechanisms-Outcome configurations (CMOc) from the realist review and interpreting the main themes to answer 'what works, for whom and in what context?' Each section in Chapter 6 is structured by presenting the topic's narrow context, its main theme and related CMOc followed by a summary.

Pawson *et al.* (2005) advise that multiple sources should be used when collating evidence. In this thesis, this has been achieved in the collection of data by undertaking fieldwork, consulting a variety of stakeholders, policy documents and clinical guidelines, as well as bringing together the broader contextual evidence from the previous chapter to situate the results. The

realist review's CMOc are used to interpret the case study results. A CMOc for each macro-theme is presented. These become the newly refined theory and are discussed in Chapter 8.

By using the mechanisms for monitoring from LMIC contexts and transferring them to the rural South African context, further 'middle-range' theories can be explained. The mechanisms established in the realist review apply to both patients and health-workers. The macro-level themes that emerged from the thematic analysis are discussed using one or more of the review's nine mechanisms. The assumption made by the school of realism put forward by Pawson and Tilley (1994) is that mechanisms can be transferred between contexts. This provides the rational argument for why something learned about the phenomena in situation A, might apply to situation B. The transferability of mechanisms is exactly why it is worth doing realist research. In the social world, where mechanisms can be conceptualised as a response to resource, mechanisms are transferable too. It has been hypothesised that the ways in which patients responded to mHealth technology in the studies in the review can be applied to the responses that patients and health-workers may have to similar digital technologies. Data to support, refute or refine the hypotheses from the review will be achieved.

This chapter will address some of the possible mechanisms that cause change or outcome (response or the reasoning to the resource) in search of causality. From these, recommendations can then be made to assist designers and implementers in developing future mHealth interventions.

Structure of the results of Research Question 2

Research Question 2 focuses on the current use of phones and computers by patients and health-workers, and the reasons for use (non-health and health-related).

Research Question 2.

How are digital communication technologies currently being used by patients and health-workers to enhance the delivery of primary healthcare within rural South Africa?

The following themes will be covered in Research Question 2:

- Patients’ current use of mobile phones and computers:
 - General everyday use of mobile phones and computers
 - Health-related use of mobile phones and computers
- Phones used to support chronic disease management:
 - Patient education
 - Adolescent mobile phone use (informal)
- Health-workers’ current use of mobile phones and computers:
 - Nurses’ use of computers

Web-literacy of health-workers Phones used to support doctors' work practices Digital solutions to drug stock-outs Drug stock-out campaign Local digital innovation by doctors Mobile apps

Further examples of each theme are presented in Appendix 9 B.

6.2 Results for Research Question 2: Current digital technology use

The general use of mobile phones and computers by patients in everyday life

Before the macro-themes are presented, patients' use of mobile phones and computers for general everyday life and specifically for health-related purposes is discussed.

Mobile phone ownership

It was useful to understand the type of mobile phones used in relation to participant responses. Many were forthcoming in showing us their phones, which were often stored in pouches on strings, bags, pockets or in their brassieres. Brands of phones included Nokia, ZTE and Samsung.

It was evident that people used their phones for different reasons and functions. This included making and receiving calls or text-messages,

listening to music, searching the Internet, for social media and using the phone's calendar, alarm and calculator.

It was uncommon for patients to not own a mobile phone. Several of the older patients did not always carry their phones with them because either they had forgotten it or left it at home on purpose because the battery was flat.

‘I go with it, but I have forgotten it today.’ (*Nkateko patient 1, female, 50–59*)

Table 25, describes how patients and community members are using their mobile phones in general in the Agincourt community, presented under micro-themes.

Table 25. Micro-themes and an explanation of phone and computer use by patients

Micro-themes	Explanation and evidence from patient/community member for general phone and computer use
Phone sharing	<p>Ownership of one mobile phone, shared between several members of a household was uncommon, as most people owned their own mobile phone. Evidence of people borrowing phones occurred when airtime was limited or phones were broken.</p> <p>‘She uses mine [<i>phone</i>] because of airtime.’ (<i>Nkateko patient 6, male, 50-59</i>)</p> <p>One pregnant woman said she shared her phone with her husband and therefore did not have access to it full-time. She was one of the few patients to not own a personal phone.</p> <p>‘It’s not with me for now, it is with my husband but I still use it.’ (<i>Pregnant woman 38, 18-24</i>)</p>
Types of mobile phones	<p>Very few people were using their phones to their full functionality often because they did not have the skills, capability or interest.</p> <p>‘The phone that I am using now is not a modern one. I used to have the phone that I use to chat with people.’ (<i>Pregnant woman 40, 18-24</i>)</p> <p>Damaged phones were common and for younger people this usually meant resorting to using an older, more basic phone (a device with basic phone functionality e.g. text-message and voice, with very limited computing power, few connectivity options and a basic user interface and numeric keypad). Some patients acquired second-hand phones through the recycling of other people’s old phones.</p>

Number of mobile phones/SIM cards	<p>Ownership of more than one phone was common. Each phone had a SIM-card on a different network.</p> <p>‘Sure but I have got three. One powerful cell phone, but I prefer this one [<i>points to basic phone</i>] to the powerful phone. I don’t have time to play with that [<i>modern phone</i>].’ (<i>Nkateko patient 6, male, 50-59</i>)</p> <p>One patient felt the basic phone is easier to use than the function phone (a midrange mobile device with a graphical user interface, basic apps, and more numerous connectivity options than a basic phone).</p>
Ability to use the mobile phone (appropriation of technology)	<p>There was an assumption by the patient that limited phone use or poor technological understanding was because they had not been educated at school or because of their age.</p> <p>‘I use my phone to receive calls from my friends and also church members. I don’t use it for anything else because I am not educated.’ (<i>Patient 42, female, 40-49</i>)</p> <p>A large proportion of patients could not write text-messages, nor had a willingness or interest.</p> <p>‘I don’t know how to write it and no one has ever taught me.’ (<i>Patient 21, female, 60-69</i>)</p> <p>There was a lot of rudimentary phone use. The type of use that mobile phones were originally designed and intended for - communication.</p> <p>‘Receiving calls, nothing much because it doesn’t do the Twitter or Yahoo, it’s just to receive calls.’ (<i>Pregnant woman 43, 30-39</i>)</p>
Assistance in using the mobile phone	<p>Peer-to-peer and assisted learning was a recurrent theme. For example, grandchildren played a significant role in supporting their grandparents with technology.</p>

	<p>‘I use my phone to call my siblings and relatives. When I want to call them, I give the children to dial it for me because I am unable to do it.’ (<i>Nkateko patient 33, female, 80-100</i>)</p> <p>One mother suggested that her children borrow her phone to use the Internet to help with homework. She uses this opportunity to get them to teach her what to do.</p> <p>‘I am still learning about it. Sometimes when children at home come from school, they do use my phone to write homework and they are showing me how to do it but I forget because it’s still new to me. I just imitate what they are doing on the phone.’ (<i>Patient 44, female, 30-39</i>)</p>
Voice phone calls	<p>Voice calls are made usually for greetings, giving an important message or having a chat. Greetings are a part of cultural life for the Shangaan people. It was unsurprising that many people expressed that the sole purpose of their phone was for simply greeting others.</p> <p>‘There is always a purpose of greeting or letting them know something, if there is anything to tell.’ (<i>Patient 23, female, 50-59</i>)</p> <p>A reoccurring theme was the intrinsic value of a person’s phone. A patient described access to her phone as ‘making life less stressful’ (<i>Patient 37, female, 60-69</i>). The phone enabled her to always be in touch with her family and gave a sense of reassurance.</p> <p>‘I like chatting to my family because I am not staying with them. Every morning, I have to call them and check if they are okay or everything its fine at home.’ (<i>Patient 52, female, 40-49</i>)</p>

<p>Text-messages (SMS)</p>	<p><i>Patterns of text-message use</i></p> <p>Younger participants who expressed text-message use, were asked to give examples of how they shortened text words such as ‘How are you doing? = HUD’ or ‘love = LUV’. One patient explained that it was dependent on who the recipient was whether she wrote in full or short text. A pregnant school-going woman said only her age cohort understand these abbreviations.</p> <p>‘When I’m chatting with young people, I write in text but when I’m sending to older people, I write in full so that they understand.’ (<i>Pregnant woman 51, 18-24</i>)</p> <p>Older pregnant women were uninterested in writing text-message as this was not something they wanted to learn ‘I do not want to do it and do not want to try’ (<i>Pregnant woman 56, 25-29</i>).</p> <p><i>Mobile payments</i></p> <p>Using the phone for mobile banking was evident but not common.</p> <p>‘If there is money that has been deposited on my account, I am able to see that there is money on my Nedbank (A South African bank) account.’ (<i>Patient 3, female, 50-59</i>)</p> <p>In one of the FGDs, a pregnant woman described how she used her phone to buy electricity and airtime.</p> <p>‘I will Dial *130*321# then it will ask me what I want to buy, they list that you want to buy electricity or airtime or pay accounts, then I select that I want to buy airtime.’ (<i>Patient 25, female, 60-69</i>)</p>
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	<p><i>Promotions and competitions</i></p> <p>People entered competitions to win prizes on their phones. This was a popular pastime.</p> <p>‘When there is a competition like for “Omo” (<i>washing powder</i>) or “Rama” (<i>margarine</i>), I do send the text-message.’ (<i>Patient 57, female, 30-39</i>)</p> <p>Some people were nervous about receiving fraudulent a text-message suggesting they do not always trust the sender or source of the message.</p>
Internet	<p><i>Lack of understanding about the Internet</i></p> <p>Many people could not explain what the Internet was. At best, they had heard the term because a family member had used it but they did not know how to describe it.</p> <p>‘They call it chatting, but I don’t know it.’ (<i>Patient 25, female, 60-69</i>)</p> <p>‘I understand that on the Internet you get different things on it, like information from outside our country.’ (<i>Patient 29, female, 30-39</i>)</p> <p>There was a perception by one woman that being able to use the Internet would enable her to see ‘what life is like outside’ (<i>Pregnant woman 30, 18-24</i>). The term ‘Google’ (web search engine) was described as ‘something that you find information from somewhere.’ (<i>Patient 50, female, 18-24</i>).</p> <p>Some patients with Internet-enabled phones were not sure how to use them or could not afford to buy data.</p> <p>There was also the idea that using the Internet is very time-consuming.</p>

	<p>‘I think I will be wasting money because it needs money to go to Internet, and I don’t have money.’ (<i>Patient 18, female, 30-39</i>)</p> <p>Sometimes their families were trying to teach them how to use the Internet on their phones.</p> <p>‘I am still trying to learn how to use it. I think I am a slow learner because my kids are trying to teach me but I’m not coping.’ (<i>Patient 52, female, 40-49</i>)</p> <p><i>Use of the Internet</i></p> <p>More rural based women were using the Internet to look-up information about life: college course, jobs, weather, music, meanings of words, medication and pregnancy. There was a trend that young people who bought data to use mobile apps but did not use search engines. This was partly because they did not understand how to search online or currently did not have a perceived use for them. Internet-users were consuming online resources for different purposes and ways. They could only search in English and not Shangaan. This assumes a certain level of education and literacy for online users, widening the gap between Internet-users and non-Internet users.</p> <p>A school-going pregnant woman said that her teachers encouraged students to use their phones to assist with homework.</p> <p>‘Like if they have given us a homework and they tell us that we have to Google it.’ (<i>Pregnant woman 7, 18-24</i>)</p> <p>She said that most of her friends at school had Internet-enabled phones and search for weather forecasts or to find educational courses.</p>
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Social media	<p>Mainly adolescents discussed social media. It is a well-known phenomenon that the younger generation are technology savvy and more competent users. However, whether this held true for younger patients and pregnant women living in this rural context was unknown. WhatsApp, Mxit and Facebook (messaging platforms) were the most common forms of social media applications participants discussed. A pregnant woman explained that the medium of WhatsApp is a better resource than text-messages because it is cheaper.</p> <p style="padding-left: 40px;">‘For WhatsApp, it’s easy to answer me right now if you have megabytes, if it’s an emergency you are able to talk to me right away but for text-messages it will take time because it can happen that you don’t have airtime.’ <i>(Pregnant woman 38, 18-24)</i></p> <p>Messaging apps are enabling easier, quicker and cheaper communication than was possible before.</p> <p>A community member who sews clothes said it was the younger generation, who use social media.</p> <p style="padding-left: 40px;">‘The older customers, they are just phoning me and the younger ones they use WhatsApp.’ <i>(Community member 167, female)</i></p> <p><i>Non-users of digital social media</i></p> <p>Many people, who considered themselves non-users of social media, had actually tried in the past and had valid reasons for not wanting to continue. A pregnant woman explained she does not use Facebook anymore because it is too easy to talk to strangers.</p> <p style="padding-left: 40px;">‘Sometimes you do chat with people that you don’t know.’ <i>(Pregnant woman 58, 25-29)</i></p>
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	<p>This was reiterated a number of times by young adults who had negative experiences of online use and were now infrequent users.</p> <p>‘It’s because when I use it, I will always concentrate on the phone and it will disturb my studies; I will not concentrate on my studies. But I have it on my phone.’ (<i>Pregnant woman 13, 18-24</i>)</p> <p>Parents were also hesitant of their children using phones to chat because it is seen as a distraction to their schoolwork.</p>
Email use	<p>Overall, access to email was rare. The minority that owned phones capable of email did not know what it was or had no need.</p>
Computer use	<p>Very few participants owned a computer. Some had done computer courses to improve their job opportunities. Learning computer skills is a highly valued ambition amongst youth. There was an idea that all technology is good and will solve problems.</p> <p>‘Like now it’s technology that is working in the whole world, so I will like to know better about the computer.’ (<i>Pregnant woman 43, 30-39</i>)</p> <p>One participant’s ambition was to get a job where she could use a computer just to ‘swing around in a computer chair.’ (<i>Patient 11, female, 18-24</i>)</p>

Social reasons for using mobile phones

The findings in Table 25 suggest that there were varied levels of mobile phone use amongst patients and community members. As anticipated, adolescent users were more competent Internet and social media users in comparison to older people, who often needed assistance with their phones. Agincourt is an area of social isolation, with limited activities for youth (Sedibe *et al.*, 2014). Mobile phones give people something to occupy themselves with, especially if unemployed. In the clinic queue, participants often said they will be ‘chatting, eating or using my phone’ (*Pregnant woman 39, 30–39*). One female said that her boyfriend, a migrant copper miner, bought her a mobile phone because she was lonely. She had personified her phone as her ‘friend’.

‘It’s my friend when I am bored and I will just press my phone and I smile. I don’t have a friend, and then my cell phone is my friend.’

(*Patient 11, female, 18–24*)

Despite this diverse phone use, a commonality amongst patients was the need for airtime. More often than not, patients expressed a lack of airtime, which caused turmoil when it ran out. They had become reliant on the ability to instantly communicate with other people.

Availability of airtime phone credit

At the time of interview, the majority of patients did not have airtime. This zero-airtime state lasted between two-days and one-month. The purchasing

of airtime was often irregular which was problematic when they became dependent on it as it gave them a feeling of security.

‘Yes, it [*airtime*] is very important and I need it but it’s just that I don’t have money.’ (*Pregnant woman 40, 18–24*)

‘I always have airtime, I cannot live without airtime.’ (*Nkateko patient 6, male, 50–59*)

Older women explained that they had no need for airtime because their phones were for receiving calls only. There was no pattern in how much people spent and how long the credit lasted.

Mobile providers are constantly advertising airtime deals. This is another reason why people have multiple SIM cards, switching between networks, depending on that week’s deal.

‘On Vodacom when you recharge with R5, they give you ten SMS.’ (*Pregnant woman 38, 18–24*)

Determining the average amount of money spent on airtime for this cohort is a difficult calculation because everyone had different needs and financial capacities. However, it was evident that most people usually bought small increments of airtime more frequently than overload their phone. The reasons for this are twofold: people were concerned that they could use up all of the airtime too quickly, or if their phone was stolen or lost they would lose the airtime. Another person said he always kept ‘R5 for emergency airtime’

(*Nkateko patient 45, male, 60–69*). This expenditure depended on his family situation that month. One woman said her airtime only lasted for a brief time because ‘when I call people it’s expensive and I talk a lot’ (*Pregnant woman 31, 18–24*). Many explained that they had to wait until they had received their social grant to purchase airtime.

‘I will buy it today after getting my grant at the shop nearby.’ (*Nkateko patient 1, female, 50–59*)

Airtime was also a commodity that was shared. Participants expressed buying phone credit for others, either by buying an airtime scratch card or by sending airtime phone-to-phone called ‘Me-to-You’. Airtime was purchased in a variety of ways, from street stalls to cash machines. It was evident that people did not have to travel far to buy airtime. Some people bought airtime in bulk and then sold it on but the profit ‘is too little’ (*Pregnant woman 48, 25–29*).

‘I like buying at PEP store [*goods shop*] because it is so cheap.’
(*Pregnant woman 47, 18–24*)

There were some people who agreed they were ‘wasting’ too much money on airtime. One patient explained that the prices were getting cheaper ‘now it is easier, maybe these companies realise something because the charges are a little bit lower than five months back’ (*Nkateko patient 6, male, 50–59*). Since people bought airtime in such small increments, even if they were able and

wanted to use the Internet they did not have the financial capacity to buy extra airtime to convert to data.

There could be long ‘drought’ periods when people could not afford airtime. This affects how much they can do with their phone and it can have implications, especially when patients become reliant on their phones for health-related uses. The appropriation of technology was often guided by peer-to-peer learning. However, this was shown to be tedious for both parties: for the grandchild who teaches their relative and for the grandparent who is learning the new skills. This ‘proxy access’ involves getting someone to support them to use their own phone. The majority of older people had never heard of the Internet or had heard the term but could not describe what it is.

In line with Hampshire *et al.* (2015:19), ‘maintaining airtime was a serious challenge for young people with limited resources’. Affordability did not appear to be a major obstacle to mobile phone ownership because people would recycle hand-me-down phones. Sometimes patients would describe sacrificing buying snack food like bananas to buy airtime instead.

Health-related uses of mobile phones

The use of mobile phones for health-related purposes is a fairly unexplored area of research in South Africa. Mobile phones are the most common

technology utilised in relation to health by patients in informal and self-initiated ways. The study aimed to ascertain people's reasons for using their phones for health utilisation and associated behaviours in doing so.

Current digital communication between patients and health-workers

There were many examples of patients contacting health-workers for health-related reasons. The most common form of communication was a mobile phone call. In some clinics, the nurses' mobile numbers were displayed on the walls.

Reasons for phone calls between patients and health-workers

'I do have their numbers. When I have a problem and I phone them, they will tell me that you have to come to the clinic early in the morning, I will treat you as soon as I arrive.' (*Patient 86, female, 60–69*)

There were examples of patients calling nurses to see if their medication had arrived.

'Yar, sometimes they phone us and ask 'has my medication arrived?''
(*Nurse 71, female*)

The ability to have access to a phone was extremely important in emergencies, when patients needed to phone a nurse directly.

‘Let’s say I have pains, like now that I am bleeding; I will be able to call and tell her [*the nurse*] my problem and ask what I must do.’

(*Pregnant woman 56, 25–29*)

Alternatively, patients phoned the nurses on the clinic fixed-line phone when they had forgotten their appointment date or for clinical reassurance.

‘OK, maybe they have given me the Zidovudine [*an ART drug*] instead of Nevirapine [*an anti-HIV drug*]. I ask the nurse here at the clinic and she told me that they have changed the treatment, so when I arrive home, I call my sister, a nurse to ask her ‘Is it ok they have given me that tablet?’’ (*Patient 15, female, 30–39*)

Nurses also phoned patients about urgent tests, such cancer screening.

‘Even here at the clinic, when they want to test us for Pap smear [*Papanicolaou cervical test*]; they call us on our cell phone.’ (*Patient 14, female, 25–29*)

More often than not nurses had to revert to using their personal phones to contact patients about their test results when the clinic phone was down.

‘Maybe TB patient, if given a return date and then they do not come, I am worried why the patient is not coming and reminding them to come.’ (*Nurse 69, female*)

When the electricity was off, which happened regularly during summer rainstorms and load-shedding (an attempt to reduce power consumption at

peak times of the day), nurses used the torch on their phones to find medication in dark storage cupboards.

6.3 Macro-themes around mobile phone use for health utilisation by patients

Several macro-themes (grey boxes) have emerged around phone use for health utilisation and these are discussed with a CMOc (blue boxes) presented.

Theme 1: Phones used to support chronic disease management

Patient medication and appointment reminder systems

Patients had various strategies for remembering to take their medication and attend clinic appointments. This sometimes involved using their phones as a digital reminder in combination with other reminders such as family support. If patients forgot their appointments, this increased patient-load because they arrived on the wrong day. Likewise, if patients forget to take their medication and default, this can be detrimental to their health condition and, potentially, also to the community. Reminder systems, particularly that involve digital prompts, improved a patient's ability to self-manage their disease or pregnancy.

The current system involves a nurse giving a patient a clinic card or book to take home with the date of their next appointment.

‘It’s always on my mind when I will go back.’ (*Patient 23, female, 50–59*)

The diagram (Figure 22) illustrates the different patient reminder systems.

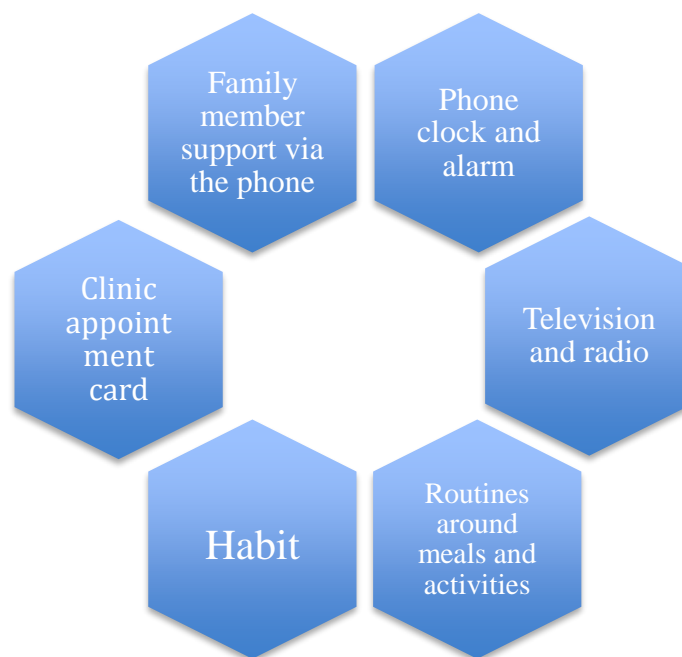


Figure 22. Diagram to illustrate the different methods of remembering to take medication or attend a clinic appointment

Family member support via mobile phones

Family members acted as treatment supporters by contacting patients via their mobile phone. A hypertensive patient explained that without this phone support he would have struggled to manage his condition as productively.

‘When I arrive at home, I will phone my children and tell them my appointment day, then they will tell me a day before by calling me and say don’t forget your appointment tomorrow.’ (*Patient 137, female, 50–59*)

Grandchildren were often responsible for reminding older relations to remember their treatment regimen, either in person or over the phone.

‘Children remind me to take. I did tell her that she has to remind me to take the treatment and she is in Grade 3 (*age 8–9*).’ (*Patient 25, female, 60–69*)

‘I am taking my pills after eating the soft porridge then my son will give me the tablets to take.’ (*Nkateko patient 97, female, 80–100*)

Another example was patients receiving a reminder text-message from a family member, usually when they lived alone.

‘Let’s say I am taking my treatment at eight, one will send an SMS at 7h45 or someone will phone me at exactly eight to remind me.’ (*Patient 137, female, 50–59*)



Photo 18. Mama Miriam and Mama Matlala in their home, using a mobile phone to set their phone alarm

Phone clock and alarm

It is not common for people to wear watches in this region. Many expressed the usefulness of having a mobile phone to check the time to know when to take their treatment.

‘When I am sitting and think about the time, I am taking my medication at eight in the morning; when I look the time at my phone and find that it’s eight I know that I have to take my treatment.’

(Patient 50, female, 18–24)

Some patients used the phone alarm to alert them.

‘I set an alarm and when it rings I know that I have to take the tablets.’

(Patient 8, female, 60–69)

Sometimes patients described this same routine but needed a family member to activate the alarm for them.

‘My children have set an alarm to remind me, when its 7h00, the alarm will ring and I will know that it is time for my treatment.’ *(Patient*

136, female, 40–49)

Television and radio

Many people described remembering to take medication when their favourite daily television programme was on.

‘I take my treatment at seven in the morning and I listen to the radio and when it’s seven, I take the tablet. I take my treatment very well.’

(Pregnant woman 31, 18–24)

Routine around food/activities

Daily routine around eating, sleeping and washing also acted as reminder systems.

‘When I wake up in the morning I cook soft porridge or tea and after breakfast I take my treatment. During the day I eat pap [*cooked maize*] and take the tablets because if I can take them without food I feel dizzy.’ *(Patient 4, female, 30–39)*

‘I drink my tea and after that I take my tablets. I know that I have to take the treatment.’ (*Pregnant woman 35, 30–39*)

No reminder system needed

It was a common response for patients to adamantly say they never forgot because taking treatment had become a habit.

‘I do remind myself because I am the one who is sick.’ (*Patient 8, female, 60–69*)

‘I am managing my condition well because I have accepted my status and I am living a normal life like everybody because I have heard that I am not the first and the last person to have HIV; I have to accept it.’ (*Pregnant woman 9, 25–29*)

Therefore, not all patients felt that they needed a reminder system.

‘Your mind and body will tell you that no something is missing. It is easy to remember.’ (*Nkateko patient 6, male, 50–59*)

Patients who regularly forgot to take their medication or attend their appointments were often able to explain the reasons for this. Psychosocial factors affected adherence. Life stressors were a recurrent theme, including bereavement, care-giving and unemployment. These major life incidences

impacted on the patient's ability to continue managing their condition effectively. Participants commonly described how stressors of daily life made it harder to pay attention to their personal health needs and adhere to treatment, particularly when managing comorbidity.

The informal reminder systems involving a phone to support the management of a chronic disease or pregnancy proved very supportive to the Vutivi patients. To test whether this held true for formal mHealth reminders, interviews were conducted with a cohort of patients involved in a trial receiving a digital reminder.

The Nkateko mobile phone call/text-message reminder intervention for hypertensive patients

The Nkateko trial is an example of how the current mobile phone practices described can be built on to form digital health solutions and interventions within primary healthcare. The mHealth component of the trial was a mobile phone call from the LHW to the patient's personal phone (Box 10) as an appointment reminder.

Nkateko digital reminder procedure

- One of the main purposes of the call was to follow up patients who had forgotten their appointment.

- Carefully framed clinic text-messages were initially sent via text-message, but after the first week this was terminated and replaced by phone calls. The majority of patients were illiterate and reliant on their grandchildren to read messages to them.
- The LHWs explained that most patients whom they had reminded did not miss their appointment (unless there was a reason such as attending a funeral).
- If the patient forgot their appointment despite being digitally reminded, the LHW would contact them by phoning to again remind them.
- The digital reminder was in addition to the clinic appointment card reminder.

Box 10. Description of the procedure of the Nkateko mHealth component

LHWs’ and patients’ general perceptions and experiences of the mobile phone call appointment reminder

The overall patient response to the voice call reminder was positive. LHWs were very enthusiastic about the trial, reporting that the system was easy to use and was improving attendance rates. They expressed that it was helping the workload of the nurses.

There were times when LHWs could not get through to the intended patient because their number had changed or they had lost their phones. It was not a fool proof way of contacting a patient.

‘They have tried to call me but my phone was on voicemail, and they were using the old number that I use in the past I have lost the phone.’

(Nkateko patient 139, female, 60–69)

Description of patients who would forget their appointments

It was hard to determine the type of patients who were forgetting to attend. Some patients were incensed that the clinic thought that they might sometimes forget. One patient said he would not forget ‘to collect my groceries’ (referring to his tablets).

Acceptability of using phone calls and text-message to communicate health-related issues

The majority of participants were comfortable with receiving the call and no technical difficulties were reported. Although two patients said they had not received the call because their phone battery had died or they had lost their phone. A key finding was that the phone call was both reassuring and motivating to patients to continue with treatment. The feeling of social connectedness and motivation was created by the supportive content and demeanour of staff over the phone. This was in line with Leon’s *et al.* (2015b) findings of digital reminders for hypertensive patients in Cape Town.

‘I felt happy because they have done things that are going to help me.’

(Nkateko patient 6, male, 50–59)

‘It reminds and encourages me to come to the clinic. When they call me it makes me motivated to come to take the treatment.’ (*Nkateko patient 22, female, 30–39*)

Some patients expressed that they felt happy that someone was checking and giving them encouragement. Sometimes, albeit infrequently, patients responded to the LHW via text-message, thanking them for the service or confirming that they would attend.

Patient appreciation of the voice call

Patients valued the polite tone of the message or phone call. This appreciation was described by one patient as reinforcement of how important attending the clinic is.

‘Even if I have forgotten or want to do something on the day, I will know that it means it’s serious as they even phoned me.’ (*Nkateko patient 139, female, 60–69*)

The mHealth intervention gave the patients confidence in the health system.

‘They phoned me yesterday I said thank you to them because I nearly forgot. I even appreciated it to them. We like that style, that system of working.’ (*Nkateko patient 6, male, 50–59*)

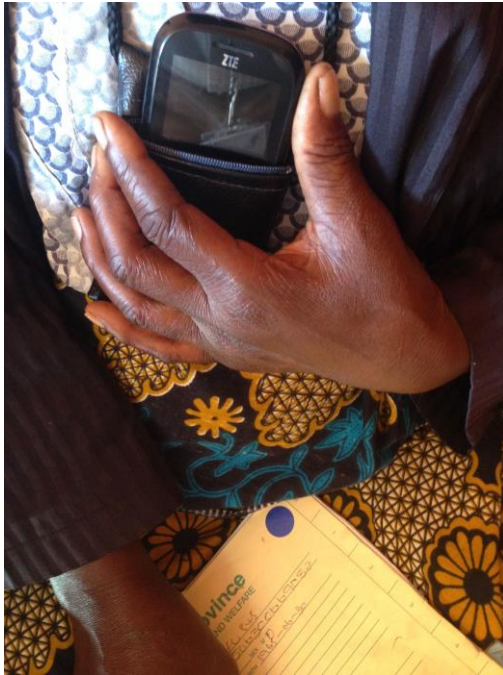


Photo 19. Nkateko patient holding her phone and patient file

Patient ambivalence towards reminder systems

However, as with any trial, there were a few patients who reported an initial ambivalence towards receiving the calls. This was partly because they felt that they already had a reliable reminder system in place or considered themselves adherent to collecting medication. Nevertheless, they still praised and appreciated the usefulness of the reminder calls. Those who acknowledged occasional lapses in adherence explained that the phone call was valuable.

Issues with the digital reminder system

One patient said that she could not answer calls during work time because she was a farm labourer, so appreciated that the LHWs left a voice message. The clinic could not rely on getting through to all patients who had phone issues.

‘I think they did call and my phone it’s not working very well nowadays, it sometimes switches itself off. Then when I came today to the clinic, they told me that I have missed my appointment; I was supposed to come yesterday.’ (*Nkateko patient 33, female, 80–100*)

As was the case in Leon’s *et al.* (2015b) mHealth study, there was an appreciation of having a choice of languages for the text-message content.

mHealth reminder to support chronic disease management summary

In the course of narrating their experience of the intervention, the patients said this was a feasible and acceptable modality for appointment reminders. This could potentially extend to educational adherence messages in this rural area by assisting in the continuity of patient care, if the person receives the call and acts upon it. It also creates an active relationship between the provider and the patient, ensuring that a continued healthcare pathway is maintained. It is unlikely to be a two-way form of communication since many patients were often without airtime and could not respond to a call or message. When people cannot afford airtime this may have severe implications as people may become accustomed to using their phone credit for health-related purposes.

Phoning all chronic patients to remind them may not be sustainable for DOH budgets and human resources considering the high numbers of chronic disease patients across the country.

Improving the poor communication between patients and health-workers

Missing appointments and failing to adhere to treatment are associated with adverse health outcomes (Rastegar *et al.*, 2003). Goudge *et al.* (2009) suggest that providers can engage with patients in a way that strengthens the therapeutic alliance. mHealth interventions can achieve this by making the patient feel connected to the system. This could be extended to formal monitoring and adherence advice as argued in the realist review. This may also improve effective communication between patients and health-workers (Freeman *et al.*, 2003). Social support in the form of digital communication may be a useful addition to the clinic reminder and increase ‘social connectivity’ (Katz *et al.*, 2015:711).

Some Nkateko patients said that they discussed the reminder call with others in the clinic queue, agreeing that they appreciated the new system because it was becoming a positive part of their healthcare experience. The trial had not been going long enough for the Vutivi study to find patterns of compliancy such as boredom, irritation or indifference to receiving the phone call. The cohort of hypertensive patients was also older; if younger patients had been

interviewed perhaps they would have been more receptive to receiving a text-message over a phone call.

Some people benefited more than others from the reminder phone call intervention, particularly those patients with greater life stressors. Patients balanced multiple stressors related to their personal, family and socio-economic circumstances and reported a range of intentional and unintentional non-adherence barriers. Stressors were apparent for those caring for sick children or other relatives and those who were bereaved of family members in short periods of time. Leon *et al.* (2015b:8) explain that sometimes, ‘non-adherence is a result of factors very difficult or impossible for a patient to control’. The impact of digital reminders is embedded in a wider environment of adherence support, so an understanding of the complex factors influencing non-adherence (poor monitoring) needs to be reconciled.

Developing a more robust reminder system

In line with Leon *et al.* (2015b), some patients did not feel a strong need for an additional reminder system because they considered themselves adherent to collecting medication. Participants reported putting in place practical measures to improve their adherence, such as writing on calendars, getting children to remind them or setting phone alarms. Results concurred with Crankshaw *et al.* (2010:732), in that ‘use of the cell phone alarm function was a commonly mentioned strategy for remembering to take medication on

time'. A few patients acknowledged that they had weak or no reminder systems. For those, the message or call helped them to become more organised and to develop more robust reminder systems. Patients who had been on chronic treatment for a significant period of time and were now in a management routine, felt that their adherence behaviours had become normalised.

The CMO for the theme 'phones used to support chronic disease management' is most akin to the CMO of the realist review on patient digital monitoring. The digital reminder promotes reinforcement, resulting in the behaviour to respond to it. The context as a pre-existing structure may or may not influence the mechanisms. In this instance, the context does act as a stimulus. For example, currently the ability to communicate remotely and digitally does not always exist. When a digital reminder aimed at reinforcing and reminding the patient occurs, this can generate a change and the intended outcome.

Theme 1: Phones used to support chronic disease management

C¹ – lack of remote communication between patient and health-worker. Risk of patients missing appointments and failing to take medication.

M¹ – reinforcement and feedback reminders. For example, Nkateko reminder phone call to attend clinic appointment.

O¹ – improved patient outcomes/appropriate adjustment of treatment to maximise health gain/enhanced continuity of care.

The context in which the reminder system may not work is if the patient has to wait for a treatment supporter before they can act upon it. When the patient already has an alternative reminder system in place they may be resistant to the digital reminder.

Health-related social media and Internet use by patients

This section on social media and Internet use relates to:

Theme 2: Adolescent mobile phone use (informal)

Other than mobile phone calls, there was evidence of patients using social media on their phones to discuss or access health information. The majority of patients who used social media were adolescents, but the age range did extend to 30–39 year olds. Table 26 summarises the uses of social media for health-related reasons.

Table 26. The use of social media for health-related reasons by patients

Phone/computer use	Explanation and evidence from patients for health-related phone use
Social media	Findings suggest that some patients used WhatsApp as a support group. ‘I do talk to my friends... we do chat about our treatment and some will say when I come here I was left with 3 CD4 count

	<p>but now I am fine. Then we ask why you stay for a long time without testing and so on. We do advise each other.’ (<i>Patient 44, female, 30–39</i>)</p> <p>A pregnant woman said she was using Facebook groups as a platform to retrieve pregnancy information and trusted the other Facebook users’ responses.</p> <p>‘I go to Facebook and then write my comment, like I will write ‘When you are pregnant what are the consequences?’ So people who know will comment on that.’ (<i>Pregnant woman 47, 18–24</i>)</p> <p>Often school-going pregnant women did not have megabytes of data to look things up online but did have the skills and understanding of how to use the Internet. This example illustrates that running out of airtime stunts a person’s ability to continue searching and learning.</p> <p>‘I did it once (<i>Google search</i>) and I run out of airtime, from there I never look at it again. I was looking information about pregnancy, I wanted to know what is happening when you are still in the early stage of your pregnancy and I run out of airtime. There are lot of things that I want to look at the Internet.’ (<i>Pregnant woman 51, 18–24</i>)</p>
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Photo 20. An adolescent using her phone to look up HIV information online

Health-related Internet use

The ability to use the Internet has become more feasible as many people have access to Internet-enabled phones. However, the cost of airtime to convert to data and poor appropriation of using the Internet have become barriers to web access.

Patients, who described themselves as frequent Internet-users, were asked to demonstrate, how they retrieved health information online.

‘I go to Vodacom Live and in the search bar and I write the name of the thing that I want to Google. After that they give me some options and I chose the option that I want. They [*comments on the forum*] are discussing about how to live with this virus [*HIV*], to cope and whatever ...’ (*Patient 11, female, 18–24*)

The patient explained how this made her feel relieved that she could chat openly to anonymous people on the web forum. She posted comments such as ‘Don’t mind about people whatever they talk, just follow your heart and know your status!’ (*Patient 11, female, 18–24*).

Table 27. Examples of online searching using Google

The use of Google and other search engines for various reasons related to health from the patients and pregnant women’s phones
<p>A school-going adolescent with diabetes described how he used Google to help with homework as well as to access health information.</p> <p>‘I use my phone to research about diabetes. What kind of food are you supposed to eat and how to prevent it and stay healthy all the time.’ (<i>Patient 129, male, 18–24</i>)</p>
<p>Several pregnant women said they use Google to find pregnancy information.</p> <p>‘I want to search to find out about what is going on when you are pregnant and when you have a baby.’ (<i>Pregnant woman 169, 18–24</i>)</p>
<p>Another participant used the following search terms such as ‘eat/exercise/stomach cramps’ when looking up information in Google.</p> <p>‘When I go to Google, I will write a question and then the answer will come out. I choose any answer then read it, after that I will read the next answer.’ (<i>Pregnant woman 59, 18–24</i>)</p>
<p>A pregnant woman explained she watched a programme on pregnancy that was advertised on a website to find out more.</p> <p>‘Last month I was watching TV and they were talking about pregnancy, so I go to the website they were talking about what you have to eat when you are pregnant.’ (<i>Pregnant woman 130, 18–24</i>)</p>
<p>Those using Google to seek health information stressed that it was to clarify verbal information given by a nurse.</p>

<p>‘I did Google some words like the signs and symptoms of the way I feel. It’s good because I get the information that I want and follow the instruction.’ (<i>Pregnant woman 131, 18–24</i>)</p>
<p>A pregnant school-going woman said she uses the Internet more since she stopped attending school because she had no one to talk to about her pregnancy.</p> <p>‘I don’t have knowledge about it and I am not studying for now. If I was still at school, I would talk with my friends about pregnancy but now I don’t have anyone to talk to.’ (<i>Pregnant woman 40, 18–24</i>)</p>
<p>One pregnant woman said she shares what she finds online with others. Google searching has become a resource and reference for health guidance.</p> <p>‘It is important because we are learning things there and you are able to share with other people who are unable to go to Internet. Like me I don’t use the Internet a lot, I just do it when I have time.’ (<i>Pregnant woman 132, 30–39</i>)</p>

Health-workers’ opinions about patients’ use of their phones for health-related purposes

Doctors were asked what they thought patients used their phones for. One doctor explained that patients do not really use the Internet yet, and those that do are usually professionals, such as teachers.

‘No the majority of them don’t, I think I can probably count on one hand the number of patients ... who have a phone capable of using the Internet or make use of it.’ (*Doctor 61, male*)

Sometimes patients would come to doctors with the information they had retrieved from the Internet, to check that it was accurate.

‘The rural patients don’t do that, but some patients do check on some things and when they come to you, they tell you that they have

checked that maybe when they have had some symptoms, they are getting tired, irritable, gaining weight “OK so I checked on the Internet and think maybe it is my thyroid”. They come to you with a suggestion and maybe you can check my thyroid levels.’ (*Doctor 64, female*)

The doctor explained that, when patients are engaged in their own health, it is good for their self-management.

‘I always want patients to be actively involved in their own health so if they suggest something I always tell them I am open for discussion. I explain and check everything and then we realise your diagnosis is out and then we go to the next one.’ (*Doctor 64, female*)

The hospital manager’s perspective was that patients now have the opportunity to teach themselves.

‘Resources are available for those who want to enrich themselves with knowledge. They are too clever nowadays.’ (*Hospital manager 65, female*)

A nurse said that it would be good if patients could look up information on the Internet, but seemed wary since she did not know how to do it herself.

‘Maybe she is having the problem she wants to know the signs and symptoms.’ (*Nurse 133, female*)

Some nurses were sceptical that patients were not capable of using their phones to source health information because of poor educational levels.

‘Eish, I don’t think so, since there is this level of illiteracy and people doesn’t have access to computers and smartphones [*High-end mobile device with touchscreen, advanced computing power and downloadable apps*]. They are still going to seek help from health professionals.’ (Nurse 90, female)

The CMOc for the theme ‘adolescent phone use’ describes the informal mHealth use by adolescents to retrieve health information. This was via the Internet, using web searches or social media. In a context where patients and pregnant women lack educational resources, they are increasingly using their phones to retrieve health information that can act as the mechanisms of advice and education. These resource mechanisms, along with the reasoning of the patient, such as a social influence (chatting to a friend via WhatsApp about HIV), can increase the access and retrieval of health information, making the patient more informed. They now have access to information on their phones. This is in line with Levesque’s *et al.* (2013) theory of access to healthcare and the WHO (2006) dimension of accessibility.

Theme 2: Adolescents’ phone use (informal)

C² – the use of basic, function or smartphones to search for health-related information. In particular, the use of the Internet for web searching, social media such as WhatsApp and Facebook. Minimal airtime credit available. A need for digital channels to retrieve health information.
M² – education and advice.

O² – increased digital challenges to retrieve valid health information/secure social networks if affordable, available and accessible (timely). Improved access to health information. A more informed patient.

The context in which this does not work may include times when the adolescent is misinformed by the online information from social media.

Patients' informal digital health use summary

Internet consumption was varied and sporadic among patients. There is not yet a common culture for using mobile web search engines to seek health advice and contribute to online forums. It is significant that some pregnant women actively contribute to online conversations to inform each other. One woman used to be employed at a shopping centre in the nearest city. This could suggest that urban exposure contributed to a more skilled use of her phone compared to women who had never left their rural village. Those who were using the Internet would often share information with their peers to increase their access. There was evidence, especially, for HIV patients using online forums and social media chat groups for support and advice, as they could remain anonymous online. The experience was self-initiated and acted as a support mechanism. This was the case in Blackstock's *et al.* (2014:411) study, where women acknowledged the need for increased digital access and 'Internet navigation training'. This may link to participation in online and community adherence clubs, which have been found to be an effective model

for improving retention to treatment (Luque-Fernandez *et al.*, 2013). Younger participants explained the ease of using social media for communication, as it was cheaper than traditional text-message. For discussing health matters using messaging platforms, many described distrust as people gossiped. Social platforms were also viewed as a distraction from schoolwork. There was evidence of participants using social media to give and seek health advice digitally with peers and family. This extended the traditional means of face-to-face discussion and voice calls. Pregnant women often searched for pregnancy information online using their phones.

6.4 Macro-themes for health-workers' current use of mobile phones and computers

In comparison to the use digital technology use by patients, health-workers' use inevitably varied and in most cases was more advanced. However, this cannot be assumed. For example, before starting training a clinical associate student described her technology use as 'zero'. Likewise, a nurse described her understanding of technology as poor. This was the general feeling about technology among nurses interviewed working in rural clinics who little exposure to digital technology. The next section addresses each function of digital communication and describes how and for what purposes health-workers are using technology.

Health-workers' use of mobile phones for calls and text-messages for social and work purposes

All of the nurses used their phones to make phone calls and send messages to family, friends and colleagues. A doctor described her phone as an asset that she could no longer do without in her personal and work life.

‘I don’t think I can survive a day without my phone; it would be difficult for me for sure. I always want my phone here, especially for my patients. I always need it, I am happy to have it.’ (*Doctor 64, female*)

Evidence revealed that nurses and doctors used their own personal phones, especially in times of power-cuts and emergencies. This is an important point because health-workers have become accustomed to using their own phones as part of their everyday work practice. They were spending their own airtime because the landline systems were not sufficient.

Doctors said that the usual procedure to make a work-related phone call was to go via the hospital switchboard. This differed depending on the reason and urgency of the calls. Often their personal mobile phones were used for calls and to access the Internet. The hospital computer had very slow Wi-Fi (local area wireless computer-networking technology). The 3G (third generation of mobile communication telecommunications technology) on their phones was variable but it was still quicker to use than the computer’s Internet, thus saving valuable time.

‘I use my phone for everything. I don’t use the landline phone because you have to go via switchboard for five minutes, waiting to connect you.’ (*Doctor 67, male*)

Some of the older doctors, who did not have a smartphone, had to use the switchboard facility and fixed-line phone.

Health-worker communication with patients from their personal phones

Nurses, gave examples of using their personal phones.

‘We do sacrifice with our cell phones if there is something urgent.’
(*Nurse 68, female*)

Nurses, in particular used their phones to communicate with patients, mostly in the cases of multidrug-resistant TB and if the patient defaulted from their medication.

‘Maybe a TB patient, if I have given a return date and then they do not come, so I am worried why the patient is not coming and reminding them to come.’ (*Nurse 69, female*)

Traditional healers also explained how phones had become an important addition to the way they can communicate with their patients.

‘Sometimes you need to phone them after like after the patient has come and you start with the treatment you need to enquire “How are you today?” is everything well with the patient or not then you discuss

with the patient so that is where you start spending airtime.’

(Traditional healer, 159, male)

The healer explained that he was on two different networks because often one operator did not have signal. This could be a problem when he was out collecting medicinal plants from the bush and needed to reach his clients.

‘If you are using MTN [*network provider*] it cannot work in that place, so it is important to have two different networks.’ *(Traditional healer, 159, male)*

Health-workers’ use of airtime

The nurses said they did not mind using their airtime, exposing empathy.

‘Eh, I feel pity for the patient and for the community.’ *(Nurse 71, female)*

They expressed dissatisfaction, but there was little alternative.

‘I am spending my own money, so it is not OK.’ *(Nurse 96, female)*

The district hospital manager considered using her personal phone as a ‘donation’.

‘We [*hospital staff members*] are donating personal resources to make sure the facilities work, such as when the phone-lines are down, we use personal cell phones.’ *(Hospital manager 65, female)*

Theme 3: Web-literacy of patients and health-workers

Health-workers' use of computers, email and the Internet

Computer skills were few and far between in the rural clinics. Out of the seven clinics, only three had computers. Only one of those computers was being used daily, by a data clerk rather than a nurse. The other two clinic computers were switched off.

Computer training

One of the nurses explained, when working at another hospital in another province, she had been on a three-day computer course, but had not used one since. There was an expectation on the part of provincial policy-makers for nurses to eventually need ICT skills.

‘It is quite unfortunate that is not even included in the training environment or it is not promoted. I am not sure where the lack is but it definitely is there is a whole culture ‘that’s not my job’ that definitely impacts because at the end of the day we actually require more administrative staff. What we really want, is the clinical staff to be more involved in their own data and not separate the two.’

(Provincial policy-maker 107, female)

Many nurses suggested that they had asked for computer literacy training when they had filled in their performance sheets but had never heard back from the DOH.

‘Plus or minus 10-years back I have been writing ‘computer’ [*on the sheet*].’ (Nurse 81, female)

‘Most of us have written computer literacy in my contract book.’
(Nurse 96, female)

Nurses have been expressing in their feedback forms for years, the need for computer literacy.

‘I will be happy because I think in a computer it will be faster ... but if you are not trained you will take the whole day.’ (Nurse 142, female)

The hospital manager said that if nurses could not use computers already, it is an issue of ignorance.

‘I never went to school and learnt computers, I taught myself just through job training so if the nurses say they can’t learn ... if a person is hungry and they put food on the table and they don’t eat who must open the mouth and feed them? There has to be a paradigm shift.’
(District manager 65, female)

A doctor suggested that it is important to remember that nurses, whilst they would not admit it, are probably ‘terrified’ of computers.

‘I think computers are easy to use if you have one at home, so you are not so scared of them. I think my mother is terrified of computers and a lot of the nurses would also be quite terrified.’ (*Doctor 62, female*)

Learning how to use a computer without formal training

Most of the nurses had family members who could use or owned a computer. This meant that many nurses had differing understandings of what a computer could be used for. Some said their families had no time to teach them.

‘My son knows, but whooo [*a sign of expression*] but he never taught me.’ (*Nurse 95, female*)

The clinical associate students grasped using tablet devices for their daily work because they were trained. They had been given the tablet as part of their university course to access educational e-books.

‘The tablet [*device*] is so useful since we are studying we are able to ask a lot of things. If you are stuck with a patient you can check what is wrong with a patient, you can look at guidelines, it is so useful. I almost use it everyday.’ (*Clinical associate student 66, male*)

Few nurses used email, partly because their phones were not capable of email.

All of the doctors used email for both work and social purposes. One doctor explained that she often emailed specialists at the tertiary hospital to describe a patient’s condition because the case was then in writing.

There was evidence of health-workers learning from one another how to use technology. For example, the data clerk tried to teach the nurses how to access emails on their phone. An older nurse said that she had an email address that her family set up for her ‘but as I am older I need children that can teach me.’ She said, ‘yes people want to be modern’ (*Nurse 168, female*). This suggested a sense of intrigue and willingness to learn.

Free Internet connection within the hospital

The doctors explained the government promised to provide Internet at the hospital. The phone line was only functional 70 per cent of the time. A doctor thought that the reason for delay was because of ‘issues of getting affordable Wi-Fi because it is so expensive.’ (*Doctor 70, male*). The doctors’ computer and Internet connection at the hospital was funded by a syndicate of doctors. They paid to use the private facilities. It was seen as a privilege because only some doctors could afford to be part of it.

‘We bought a computer in the doctor’s tea room so that’s always connected to the Internet, so people that are not having devices at the hospital like laptops, they can also use it.’ (*Doctor 62, female*)

The doctors’ thought that free Wi-Fi should be accessible in all health facilities.

‘There is almost no wireless Internet for the hospital itself. I mean I have hospital managers wanting to join because they don’t have it.’

(Doctor 62, female)

Health-workers’ access to the Internet from their mobile phones

There was a huge variation in use of the Internet. When used by health-workers, it was initiated predominately from a mobile phone rather than a computer. The majority of nurses had heard of the Internet, even if they did not know much about it or had no experience of using it. Many nurses referred the younger generation as the Internet-users, especially for job searching and social networks.

‘Those are the teenagers who use it – Facebook and what what. I don’t know ...’ *(Nurse 71, female)*

A doctor described most of his fellow doctors as ‘digital natives’, mostly comfortable using technology. There were exceptions.

‘I have got an old fashioned phone, which does not have much on it. So I am personally not using it much in consultations. I tend to look things up in books. I can see though that a lot are using it ... you know googling things when they want to know things.’ *(Doctor 63, female)*

Doctors in general are more literate than nurses in using the Internet. This can be coined 'web literacy', the ability to understand what they are looking at, where it has come from and whether it can be trusted. Continuity of care should improve if the patient or nurse is accessing valid online health information. Access to information via the Internet to check drugs or symptoms has opened up new channels for health-workers. One doctor explained the use of the Internet as a quick learning resource as 'revolutionary'.

'You kind of know what you have to do, or you are unsure how to make a diagnosis, text books you can download or view on the net [*Internet*].' (*Doctor 125, male*)

'Occasionally you may Google things to refresh your memory or to look up a differential or remember what test you need to do.' (*Doctor 146, male*)

A clinical associate said 'I go to Google for clarity before I go to the books' (*Clinical associate student 150, male*). A doctor said that she used the Internet to search for images to support his diagnosis.

'Let's say I have a patient who presents with schizophrenia, I will go through the Internet and check other symptoms and diagnosis and then I can, if I am not sure ... check the pictures and familiarise myself

with what I am seeing see what is it and how to manage it.’ (*Clinical associate student 66, male*)

Several nurses gave examples of when they had asked their children to look up information using Google, such as checking the side effects of medication for antibiotics administered for appendicitis. They did not have the ability to search for the information themselves. Others said that they used Google to look up English words related to health. If a nurse used the Internet, they explained that it was infrequent because of difficulty using it. This suggests that they are not confident users themselves and need the support of relatives.

‘Sometimes even if I want to know about HIV/AIDS, if I just Google search it, I can type that name of medication that will tell me.’ (*Nurse 92, female*)

A nurse suggested that googling is useful because there are no libraries in the rural areas.

‘So maybe you can Google and find one thing that you can not find in the books ... we do not have libraries here that are well equipped so the Internet for Google searching for health seeking is good.’ (*Nurse 92, female*)

Others gave examples of checking signs and symptoms, such as drug side effects.

‘Information maybe concerning the generic names of drugs and also say certain conditions if ever you are presenting with these, the symptoms of that condition and how to treat it.’ (*Nurse 149, female*)

Some said they understood the benefit of using the Internet but had to restrict their usage because of the cost.

‘To check, when I want to understand the diseases of my clients, I just search but not always because it is expensive.’ (*Nurse 73, female*)

The CMO for the theme ‘web-literacy of patients and health-workers’ proposes that both parties are increasingly accessing the Internet to search for health information to improve knowledge. However, there is a lack of understanding about the validity of the source of the online information retrieved. To achieve improved web-literacy, the mechanisms of information and decision-support can allow health-workers and patients to use supportive digital services that contain accurate and reliable material to make informed decisions about how best to treat a patient or monitor themselves.

Theme 3: Web-literacy of patients and health-workers

C³ – Patients and health-workers are accessing Google to retrieve health information to improve their understanding of a symptom, drug or disease. M³ – information/decision-support, for example, primary healthcare guidelines on new government app presents an algorithm for decision-making.

O³ – more-informed patient and health-workers using reputable source. Available to access 24/7. Improved access to valid health information.

A context that this may not work is when the patients' and health-workers' web literacy is stifled by lack of skills, cost of use or availability of technology to access online resources.

Health-workers' use of the Internet summary

The Internet has become a digital source to access health information to extend health knowledge. Although searching online for health information is a fairly new phenomenon, its uptake is slow and usually privileged to a minority. They know how to use a search engine and have the financial ability to buy data to do so in a resource-poor setting.

Some nurses accessed digital health information to look up DOH guidelines or protocols or if they needed to refer to another source for confirmation. However, a major problem with this is the validity or the reliability of where the nurses are accessing this information. This needs to be better understood because often the examples given were not trusted medical sources. Frequently, the nurses had little concept that finding something on Google did not necessary mean it was clinically accurate. This is perhaps a policy point, in that nurses with access to smartphones should be able to download free e-books such as Medscape or DOH guidelines.

These findings propose an evidence-based website under NDOH is necessary. This would ensure health-workers are guiding patients to legitimate health advice ‘thereby making access to quality information on the Web a priority’ (Devine *et al.*, 2016). Pimmer *et al.* (2014:1398) argue that mobile phones and social media converge to ‘change learning environments’ and ‘create organically grown learning practices’. This is particularly true in South Africa, where nurses ‘often work in isolation and have very poor access to post-basic education, continuing education and up-to-date evidence-based information’ (Pimmer *et al.*, 2014:1399).

Theme 4: Phones used to support health-workers’ work practices

It was evident that doctors use their personal phones to support their work practices. Their use was often self-initiated and driven by solving the daily health system challenges that they were encountering.

Digital decision-support

Doctors were using official medical applications, grounded in scientific evidence, more often than searching on the Internet. This can be perceived as

having the potential to improve quality of care if the nurse or doctor can become more informed, more quickly. Doctors referred to their phones as having information ‘in their pockets’, referring to their phones.

‘You don’t have to carry a suitcase of books with you.’ (*Doctor 62, female*)

Digital blood test results

Some doctors used the ‘Track Care’ (previously ‘Mobi-Lab’) app to access results directly on their phones. A doctor explained how receiving blood tests online had made her work much more efficient.

‘So many bloods were being repeated [*because they were lost*] and so you would have to have these lengthy phone calls to the lab and then they had to read out the results. Sometimes they actually never told you whether the blood had actually reached the lab or whether the specimen was rejected or whether they were still waiting for the tests to be done. But when you check yourself, on the app, you can check whether it was rejected, whether it had been received.’ (*Doctor 62, female*)

Another example a doctor gave was the repeated poor communication between the hospital and national laboratory. She described chasing results as very time consuming.

‘Every part of work is frustrating, so you submit something to the lab and they lose it. They have run out of forms for weeks now, so we are just using photocopies and writing on the tubes [*i.e. there is no barcode sticker*] they will lose it or very often they do the wrong test like they choose which test to do. So there is that and a bit of a communication issue resulting in the wrong test being done. Or because the photocopy is malfunctioned there is no paper to write anything down.’ (*Doctor 146, male*)

Some doctors were more advantaged than others simply by nature of owning a smartphone.

Point of care diagnosis

There was evidence of digital communication between district doctors and tertiary specialists via the medium of WhatsApp. This informal and ad hoc system sits under the umbrella term of telehealth, helping to strengthen diagnostic capabilities. If a doctor takes a photograph using their personal mobile phone of the X-ray image and WhatsApps the digital media to the specialist’s phone, the specialist can make a remote diagnosis. This should speed up the expert’s decision to accept the referral, but only if they are willing to use their personal phone. Issues of the confidentiality of patient data need to be resolved due to concerns of privacy and accountability. The

messaging platform contravenes the Protection of Personal Information Privacy Act of 2013, discussed in Chapter 2.

‘I will take pictures of the X-rays and send them to whoever is on at the tertiary hospital, they will read the pictures and that is how we will communicate.’ (*Doctor 67, male*)

It was unknown what happened to the photos of the X-ray image once the specialist had analysed them.

The use of WhatsApp as a form of communication between doctors, who have formed a WhatsApp group for the purpose of having a quick method of communicating to many doctors at once, is enabling.

‘Occasionally clinical stuff but can deteriorate into just natter. It’s great, easy free and everyone has got it and it is not allowed in the UK because of privacy and accountability.’ (*Doctor 146, male*)

Phones used to support health-workers’ work practices summary

The medium of WhatsApp came across as a very popular communication tool used mostly by doctors as those in positions of power. Its use could extend to CHWs as a platform to share and update their supervisors while working remotely and even take photographs as evidence of their practice. An app or service to make this process more streamlined, confidential and accountable

would be beneficial. This may allow for district doctors to understand future cases whereby a referral may not be necessary, improving quality of care.

The CMO for theme ‘Phones used to support health-workers’ work practices’ discusses how smartphones are creating inequality among the haves and have nots. For example, a doctor uses their smartphone to gain information (the underlying mechanism) from another specialist at another hospital about whether their patient should be referred to higher-level care by sending a secure message or photograph. If a digital response is received, the outcome should be a quicker referral, speeding up the diagnosis and therefore the time taken for the patient to be treated. By improving the digital communication between health-workers, the patient should receive faster healthcare attributed to the mechanism of specialist feedback. However, given the broader context such as poor EMS and long queues, the outcome will only be realised if external issues are resolved.

Theme 4: Phones used to support health-workers’ work practices

C⁴ – the use of smartphones by doctors during consultation. Health system problems such as referral problems.

M⁴ – information, for example, whether a referral can take place. Feedback, for example, sending a photograph or question to a specialist for remote diagnosis.

O⁴ – positive: faster referrals/quicker diagnosis. Improved digital communication between health-workers. Negative: doctors without capability and opportunity to use digital devices left behind. This is not an equal playing field.

It is a two way process - both health-workers must feel engaged and able to communicate this information. A context in which this would not work is when the other health-worker does not respond, either because they are too busy, do not have a smartphone, or the company capacity to do so.

Theme 5: Local digital innovation by doctors

Following the use of phones by health-workers in general, evidence of digital development by doctors who are trying to resolve their own problems, considering the constraints of the setting became apparent.

Diagnostic referrals using the ‘Vula Mobile’ app

An example of local innovation is the ‘Vula Mobile’ diagnostic eye app developed as innovation out of necessity. This is a prime example of development by doctors for use by health-workers. Vula is enabling diagnoses in areas where it was not always possible. It does not require a locus of skill during the first stage of the diagnosis.

Vula was designed by a South African ophthalmologist to overcome the obstacle of patient and health-worker remoteness. This is an example of mobile phones strengthening diagnostic capabilities, specifically for eye

health, where issues of rurality are a problem. There are long waiting lists for patients to have cataracts removed in the public health system. Vula allows CHWs to test people for eye conditions and refer them to a specialist. For the diagnosis to take place, the vision test involves photographing the eye on a smartphone camera and then doing a brief questionnaire about pathology and other medical history on the phone. With that amount of information, they can make a very accurate decision about what the problem possibly is and how the patient could be best managed.

The ophthalmologist explained the purpose of the app was to get greater reach to populations who are living remotely and in need of care.

‘We are targeting the health professionals who are seeing the old people. The app is designed for use by someone who doesn’t know anything about eyes. They see a patient with an eye condition and want to get advice. The app gives you a questionnaire about eyes and a vision tool guide, through a chat system. A bit like WhatsApp that connects you to a specialist who is on call. It’s only two megabytes large, so it is easy to download especially in rural areas.’ (*Doctor 147, male*)

He cautioned against the ability of the app in helping all eye cases, suggesting it was more of a decision-support tool to decide the next step for the patient.

‘I would hesitate to say that all diagnoses could be made from a simple app like Vula. I prefer to think of Vula as a way of deciding how the patient is best managed. For example, can the patient be managed by the primary care giver with advice from the specialist, or does the patient require urgent specialist attention, or does the patient require non urgent specialist attention?’ (*Doctor 147, male*)

A level of agency is necessary to encourage decision-making so that the health-worker does not miss vital indicators for referral. Secondly, if a referral is made, there have to be adequate numbers of specialists in the hospitals to deal with the increased cases of cataract operations. By improving the ways that the diagnosis is delivered, the system must not then sink under its own weight because of increased diagnoses. This digital development from within is an example of health-workers putting into practice what they need to improve their work rather than waiting for a top–down policy to change how they work.

Referrals using existing digital media

Thumela Mobile

A rural doctor developed ‘Thumela Mobile’ as he was frustrated with not being able to get through to the right specialists. The aim was to connect

health-workers, to improve referrals and remote diagnoses, using digital means.

‘A technological and 21st century solution to a third world country problem. At least then you are only contacting the most appropriate on call doctor.’ (*Doctor 61, male*)

This system enables the doctors working at different hospitals and clinics to know who is working, when and where so they can make real-time referrals.

‘The amount of difference it makes just having the access to who to call even needing to transfer a patient can sometimes cut out time spent phoning people. The very first step in the process is just to know who to call, or who to communicate with rather than the how.’
(*Doctor 61, male*)

This digital system for knowing who is on call makes the everyday health system flow better and the organisation of the doctor’s lives easier.

Local digital innovation by doctors summary

Many referrals stagnated because of poor communication between facilities. Thumela Mobile was designed as a digital work planning and scheduling tool to improve referrals. Vula Mobile illustrated local innovation by an ophthalmologist to overcome barriers to accessing services for patients in remote rural areas. The diagnostic application has the ability to strengthen

referrals, though Rotchford *et al.* (2002) found that even when patients are referred there is a poor uptake of cataract surgery.

Likewise, the messaging platform of WhatsApp is an easy and free platform for health-workers to share and communicate caseloads and assist with remote diagnosis. However, the implications for the non-secure messaging of text and photographs of patient data have to be resolved. External barriers to referrals, such as transport issues will not be resolved by digital communication systems.

Smartphones creating inequality balance among health-workers

Access to smartphones for use in clinical practice can cause differing power relations between health-workers. Not all rural doctors were in a position to own a phone capable of taking photographs, support messaging platforms and search the Internet. This put them at a disadvantage to their colleagues already using phones, for example, to access blood test results and to contact specialists. The majority of health-workers were willing to use their personal phones for work practices – and this will only increase as smartphones become more common. For those who have the capability, motivation and opportunity, as suggested in the realist review, there is evidence that doctors are developing innovative solutions to their everyday problems.

The CMO for the theme ‘local digital innovation by doctors’ is similar to the previous CMO for phones used to support health-workers’ work. The context of access to a smartphone creates the opportunity to develop and design digital solutions that use the mechanism of ‘decision-support’. The end outcome goal is to improve patient access to services via improved communication. This example supports the Capability Approach (Sen, 1990) in that a person’s capability to use the resources around them as agency of freedom will benefit them.

Theme 5: Local digital innovation by doctors

C⁵ – clinical primary healthcare setting, low-resourced. Health-worker does not have access to a work computer but has the skills. Health-worker has access to a personal phone that might be a mobile digital device such as a smartphone or tablet.

M⁵ –decision-support, for example Vula diagnostic eye app and information or Thumela referrals.

O⁵ – access to a digital device and the capability of using it as a response to needs. Innovation driven by desire to improve health system challenges with or without the support of the DOH. Improved digital communication between health-workers and patient to support better decision-making.

Contexts where this may not work are when the cost implications of using the digital solutions outweigh its benefits. This may be when only a minority of doctors are using these solutions and when innovation remains low-key and only used by the developers.

Theme 6: Digital solution to drug stock-outs

Following on from the theme of the development of digital health and systems by doctors in response to challenges, is the development of digital solutions for drug ordering systems. One of the challenges discussed is the unavailability of medication.

Drug stock-out campaign

The national ‘Stop Stock-outs’ campaign aims to assist healthcare users whose lives remain threatened by the chronic plague of medication stock-outs. Stop Stock-outs gives a voice to patients and health-workers experiencing acute medication stock-outs. Anyone can alert the campaign by calling, sending a text-message or ‘Please call me’ (free text-message), WhatsApp message or email. The campaign’s purpose is to pressurise the government into action.

‘The project is really just advocacy and pushing the government, helping them identify the problems and the gaps and then the action.

It is left to the DOH responsibility.’ (*Expert, 151, female*)

Once the information is received, the campaign escalates it to the district DOH and they have two days to resolve the issue. Box 11 presents the three reasons for drug stock-outs, according to the Stop Stock-outs employee.

- 2–3 per cent of drugs that are out of stock are the result of international manufacturing problems.
- 20–30 per cent of stock-outs are a problem at the NDOH, which has wrongly forecasted how many drugs it needs and therefore the manufacturers cannot supply it with the right capacity.
- 70 per cent of the time there are logistical challenges between the depot and the clinic.

Box 11. The reasons for the drug stock-outs (*Stop-Stock-outs, 2015*)

Forecasting estimates are done by the DOH, to determine how much medication the clinics need based on data from the previous year's consumption. One expert described the standard drug ordering system, which uses paper hard copies.

‘There is no standard system right now... definitely moving different pieces of paper around. I think there are a few hospitals that now have electronic systems and they are trying to roll-out this everywhere but you need a computer, Internet and electricity. It's a paper system so they have to make five copies of their order form and send it to different parts.’ (*Expert, 151, female*)

The financing system for purchasing the drugs is complicated because the supplier will stop delivering if payments are not made. An NGO employee said that the government is starting to respond to the campaign.

‘Over the last two and half years it has shifted the DOH's perception that stock-outs really are an issue. Now there is much bigger acknowledgment that it is a big problem and some provinces that are

doing better and others doing worse, some districts which are more affected because there are a higher burden of patients in that district.’

(Expert, 151, female)

The campaign engages with the provinces to develop action plans to resolve stock-outs. Improvements are being made in some of the worst performing provinces, such as Mpumalanga, where the Vutivi study was conducted.

‘A lot of it is just individual accountability and individual things that can’t be fixed with overall system reform... learning how to order properly or making your order on time. Having a district managers supervise clinics who were not ordering properly.’ *(Expert, 151, female)*

Solution to drug stock-outs summary

The advocacy of rural doctors in building a platform such as Stop Stock-outs is testament to the use of digital solutions to improve a health system challenge. Findings suggest that drug stock-outs are created because of logistical challenges between the depot and clinic. There is a need for a more streamlined ordering system at the facility level. Using the newly proposed government system nurses can scan medication when it runs low to alert a central database to automatically reorder the drugs. The ad hoc sharing system of drugs between clinics can become more formalised using this software platform.

The CMO for the theme ‘digital solution to drug stock-outs’ proposes that, if there is a shortage of medication at the clinic, patients or health-workers can digitally alert the campaign team about the problem, so that the situation can be resolved. The mechanism of ‘information’ acts as a trigger to influence a change by increasing knowledge. In the long-term, this improves the drug-ordering system by using digital devices to communicate the shortages.

Theme 6: Digital solution to drug stock-outs

C⁶ – poor drug supplies in primary healthcare facilities. Drug stock-outs causing delay in medication to patients who are often on long-term regimens.

M⁶ – information, e.g. Stop Stock-out campaign – collates information of where drug supplies are low or out-of-stock.

O⁶ – improved pharmaceutical and logistics supplies. Improved digital communication between clinics and depots. More patients and health-workers actively engaging in social media when there is a stock-out.

This is not a fool proof method of ensuring drug stock-outs are accounted for. Not all patients and health-workers would be able or willing to record an issue at their facility using their own personal phones.

6.5 Health-workers’ current informal digital health use of technology

Findings revealed that health-workers use their personal phones for work-related activities. Often there was no alternative as phone-lines were down or congested. In extreme cases, nurses phoned TB patients to give them their

results and the required action. The nurses said they felt pity for their community. Generally, nurses had a limited understanding of computers and the Internet, although eagerness of nurses to learn was high across the board. Nurses' web-literacy was poor. They recognised the value of being able to look-up clinical guidelines using a digital device but were unsure about where to search.

Doctors, however, were advantaged if they had a phone with Internet capability and built-in camera. They could take photographs for clinical diagnostics, join doctor WhatsApp groups, check emails and receive blood test results. However, these doctors were storing patient data on their personal phones without the patients' permission. Ethical regulation of what applications can be used by clinicians needs to be formally issued by the DOH. They could share confidential case notes via a more secure messaging service with end-to-end encryption. The doctors recognised the issues with using a free messaging platform and discussed their concerns of privacy.

‘We must be careful because you start to step the boundaries.’ (*Expert 109, male*)

Rural health-workers arguably face greater pressures within constrained and sometimes hostile working environments. These doctors were using creative digital ways to overcome issues created by this context. User-driven examples of the innovative responses to barriers in care were described. The use of existing tools to support and resolve work issues using unregulated, free

mobile messaging platforms enabled and enhanced communication between health-workers.

Conclusion of Research Question 2

This section has met the initial objective of describing and exploring with patients and health-workers the current use of mobile phones and computers.

In conclusion, mobile phones are currently being informally used to enhance primary healthcare delivery in rural South Africa as use becomes normalised in everyday practice. The CMO configurations for the themes presented support this.

6.6 Results for Research Question 3: Potential future digital technology use

Research Question 3.

What is the potential for the use of digital communication technologies to enhance primary healthcare delivery in rural South Africa?

Structure and background to Research Question 3

Research Question 3 focuses on the potential of technology as discussed by patients and health-workers. This is important in understanding what they have identified could be beneficial to their future health and work needs. The potential use of future digital reminders in primary care has already been discussed in Research Question 2. This is because current use can lead on to what has potential for the future. For example, patients' current reminder systems involving phones and evidence from the Nkateko trial can influence the design of future digital health interventions.

The following themes will be discussed.

- Patients and health-workers' future use of digital health

Patient education via digital health

Future use of eHealth and mHealth

6.7 Patients' future use of digital health

Theme 7: Patient education

Telehealth: phone call to a health-worker for advice

For many patients, the concept of using their phones for health purposes was unfamiliar. Many were already using their phones in subtle ways, such as setting an alarm to remind them to take their medication, to assist in disease management.

A woman with her first pregnancy said that she would use a remote tele-doctor as she felt it would overcome her shyness of communicating face-to-face.

‘It will be a good thing because sometimes I can be shy to see you face-to-face so if I don’t see you I will ask anything that I want to know about my health and pregnancy.’ (*Pregnant woman 38, 18–24*)

Another patient expressed a desire to speak to a nurse over the phone about her chronic disease allowing her to ask for basic advice without going to the clinic.

‘Like when I take the pills, I sweat sometimes so I will ask if the pills are OK because I am sweating.’ (*Patient 11, female, 18–24*)

‘Even when you are at home you have a question, you don’t need to come to the hospital; you can use that number.’ (*Pregnant woman 130, 18–24*)

Sometimes patients would like reassurance about how the disease or medication is making them feel.

‘They can phone there is no problem with that.’ (*Nkateko patient 27, male, 60–69*)

A pregnant woman explained that sometimes nobody at her home knew the answers to her questions and the nurses are too tired to answer her. She needed support from elsewhere. Some patients said that there were times when they needed confirmation from a health professional to make an informed decision about their health.

‘Like myself I have a husband and he wants to have sex without a condom meanwhile it’s not right, so if I have a number of a doctor or nurse I will call them and tell them what is happening then they will help me.’ (*Patient 138, female, 30–39*)

Text-message for pregnancy advice

Pregnant women were asked whether in the future they would welcome the option of receiving stage-based messaging from the government to their

mobile phones containing pregnancy information. This was prior to the launch of MomConnect.

‘If they can SMS you saying that at this stage you must use this and that, it will be good. You will end up being a healthy person.’

(Pregnant woman 38, 18–24)

Other women said it would help to increase their knowledge.

‘I will learn some of the things that I don’t know.’ *(Pregnant woman 7, 18–24)*

They would trust the text-message if it came from the DOH. A two-way service where they could reply and ask questions was expressed. A private doctor, who also worked in a government hospital, felt it was a good idea, especially for first pregnancies, because it would educate women about what to expect.

‘It is nice for them to be updated on what is happening, if it is week-by-week, what they are supposed to expect now so that they don’t get surprised. I think those message will help because it will tell them what to expect.’ *(Doctor 64, female)*

Another doctor preferred women to just remember their antenatal care bookings as they should be responsible.

‘I always try to empower them just to remember themselves.’ *(Doctor 64, female)*

The nurses recognised the usefulness of sending health information via a text-message or social media to patients' phones, rather expecting them to read clinic posters.

'Now our patients they are more technology-advanced, usually they are on their cell phones... if that information is there, it will be better for them, unlike putting the poster on the wall which they don't normally read.' (*Nurse 92, female*)

Patients suggested that the opportunity to speak to a health-worker over the phone would be a benefit to them. Sometimes they are too shy to speak to the nurses in person or raise concerns when it is not possible to go to the clinic after hours. Preventative messages from a health-worker could be linked to the possibility of earlier diagnosis. This finding links to the need for reassurance, especially in first pregnancies. There was great enthusiasm for a future service. The text-messages are not available in Xitsonga and may be disadvantaging some women in and around the study site.

Nurse's opinion of patients digital technology use

The nurses said patients do not like coming to the clinic for health advice.

'I think it is a good idea because most of the people they do not like coming to the clinics and queuing for a long line, you find that you are only there for information but you have to but then if there are

numbers like that or places they can get help without queuing think it's [*health information via SMS*] a good idea.' (*Nurse 91, female*)

Nurses thought that it would be useful if chronic patients could search for more information about their health.

'Most of the time like the chronic patient, maybe I think one day she will check what diabetes mean... what the cause and everything, yeah it will help.' (*Nurse 92, female*)

The nurse suggested that if patients need further information they could use the Internet; it does not replace them coming to the clinic.

'Maybe if they don't understand their treatment or their disease, they can access it on the Internet.' (*Nurse 93, female*)

It was important to understand the language in which people would like to receive a reminder message; the majority suggested their indigenous language or dialect.

'I prefer Shangaan because it's my mother tongue and there are other words that I won't understand if in English.' (*Patient 25, female, 60–69*)

There was a mixed reaction to digital reminders. Some patients did not understand exactly what the text-message would contain. Also, asking people's opinion about something prospectively they have never heard of, might have been why some reactions were vague or uncertain. A private

pharmacist, who also sells medication to patients using the public health system, explained that a reminder service is not going to be feasible.

‘I don’t think it really helps unless one understands the gravity of their condition. And for those that understand the gravity of their condition you find that they don’t even need reminding because they come and seek help.’ (*Private pharmacist 140, female*)

Although hypothetical, most of the patients and pregnant women expressed an interest and valid reasons for wanting to seek health advice as and when they needed. While they gained health education from the clinics, sometimes this is not enough and it needs to be extended. Therefore, digital learning to increase patient education may be a welcome resource.

Health-workers’ opinions about the potential future use of eHealth and mHealth for patient care

Health-workers were asked what they felt could be a potential future use of technology to aid communication. One nurse alluded to the ability of patients to monitor their health via mobile phone; she was not quite sure how it might work yet thinks might be possible.

‘If the patient is staying with a youth and they know his or her condition, they can check the BP [*blood pressure*]. If we say the BP is very high and glucose test is high, check on computer and cell phones.’ (*Nurse 71, female*)

Like the Nkateko LHWs, the nurses also said it would be useful if they could send a text-message to patients to remember their appointments because it might reduce defaulters.

‘They do not know how to check their return date. Then they receive SMS and it goes beep-beep and then they can say to the little ones, ‘Can you check it for me?’ Tell them to remember to go to the clinic.’

(Nurse 69, female)

The nurses thought the reasons for older patients forgetting their appointment was laziness or lack of transport money.

‘Sometimes they don’t even notice especially the gogos [*Grandmother*] and some they don’t forget they are just lazy to come for the queues. Some it is far don’t have money to come to the clinics.’

(Nurse 74, female)

The nurse’s felt using the Internet was unaffordable for many.

‘It is very important to learn about pregnancy or diabetes and acquire more knowledge. This is a rural area. They can’t even afford to buy BP cuff and check blood sugar level.’ *(Nurse 96, female)*

Sources of patient education: clinics and alternatives

mHealth offers new forms of health education and information provision. Health information can be communicated to patients from multiple sources. Often, education through locally available resources was ad hoc and often

dependent on chance. For example if the clinic actually had pamphlets available. Informal mHealth efforts, such as discussing with peers on a WhatsApp group about their condition or soliciting advice from people ‘in the know’, were examples of patients actively looking for the information rather than have it directed to them.

In this context, most patients over the age of 60 years had no concept of what the Internet was. Therefore, suggesting searching on websites may not have been an option for the large cohort of older patients with chronic disease. Perhaps text-messaging or an official health website could improve the channels through which a patient receives health education targeted to the condition. This has to be grounded in behaviour change theory and frameworks used such as, the one proposed in Chapter 3. Whether the patient is being sent a behaviour change health message or is looking up health information on the Internet, both require an opt-in model by which the patient has to want to find out more about their health.

The inability to access health information could result in a lack of patient choice, health illiteracy and a patient having an inadequate understanding of their illness. It is difficult to measure how much knowledge patients can acquire from a clinic via the daily nurse health talks or radio. This is an important policy point because it cannot be assumed that patients adequately

learn everything from the clinic. It was found that patients access health information from a variety of sources over time; the information is not consistent and is partly received at random.

The CMO for the theme ‘patient education’ describes how digital resources to increase a patient’s health education may be a useful form of communication. The broad context of the health system in Chapter 5 alluded to the lack of sources patients can seek health information. Therefore, the mechanisms of ‘education’ and ‘health promotion’ can improve access to information and promote self-regulation. This may in turn make the patient more informed and self-empowered.

Theme 7: Patient education

C⁷ – patients seek availability of health education sources from few places, namely the primary healthcare clinic.

M⁷ – education/health promotion.

O⁷ – phone line/SMS website/apps – allow patients to seek guided and valid health information from a reputable source (NDOH), bringing healthcare services/advice to where people work and live. Improved access to health information. Self-empowered patient.

This will not work in contexts when the digital information is not actually educating or promoting health or doing anymore for the patient than if they could learn it from currently available sources. The information being communicated digitally has to be well-timed and user-driven.

Theme 8: Nurses' use of computers

The nurses were asked whether they thought mobile phones and computers could play a role in future primary care. Many said technology could improve aspects of the health system and health outcomes by assisting with some of the challenges. This will require nurses to be trained in computer skills.

‘Yes, very important to have computers in the facilities in connection with services of the patient.’ (*Nurse 69, female*)

This is the remit of the National Broadband Policy (DOC, 2013:2) under the Electronic Communications Act, ‘it is critical for South Africa to ensure realisation of the goal of an all inclusive information society that can enjoy the economic benefits associated with broadband in both urban and rural areas’. As part of the future NHI scheme, all clinic computers in each province will be connected with broadband Internet to improve communication channels.

Reasons for the potential future use of computers in clinic settings

Nurses understood the usefulness of a computer in their daily work.

‘I think there is, is it is not now we are using pens and books – monthly stats, write down the data but if we had computer, we would just go

and retrieve the info to see how many under-fives we saw.’ (*Nurse 90, female*)

Several nurses expressed an interest in electronic patient records, as this would improve patient follow-up.

‘So or even the return date when to come back. So if I want to see all my patients concerning TB I can go to the system. This one came this day, this one will come that day, so I can see that this one did come, this one didn’t come.’ (*Nurse 133, female*)

The pre-packing of medication could become quicker if the patient’s treatment regime list were on a computer. A printed list could guide the nurses instead of pulling out physical files. Hand-drawn graphs were stuck to the filing cabinet of the sister in charge’s office.

‘Indicators of the duties we are doing here – immunisation of children, antenatal care booking of clients, pap smears, and TB management. Helps us to see how we are performance if our service going down.’ (*Nurse 68, female*)

A computer would be much quicker to use than hand-drawing the graphs and plotting them manually. Also, these data charts could then be emailed to the district DOH.



Photo 21. The consulting room with hand-drawn graphs by the nurses, indicating monthly indicators

Nurses were aware of the increased use of technology since they started working. They understood the need to adopt technology rather than feel reactionary towards it because of the possible time saved.

‘Yes, it’s changing; we have to change rather than resisting it. The computers it will save us a lot of things. When I want something for the patients I just click rather than paging through.’ (*Nurse 74, female*)

‘Yes computers especially the information of the patient, you see now we are even them ARTS so you can see this patient has defaulted, even able to trace them using the computer.’ (*Nurse 96, female*)

Some of the more senior nurses said they were content to carry on doing things just as they were. This suggests there may be an age discrepancy between those in favour of using computers and those who are not.

‘I am happy with the way I do things, I am gonna’ stay.’ (*Nurse 81, female*)

Some of the clinics have a data clerk whose role it is to use the clinic computer. This has created a feeling that it is the clerk’s job to use the computer not the nurses’ since they are the ones who are trained on it. They recognised that clerks do not work on weekends and therefore nurses also need computer skills.

‘Oh yah that’s why we must learn about the computer.’ (*Nurse 81, female*)

Future use of technology and the resistance to change by older nurses

When it came to using computers in the clinics, there were mixed views on how older nurses would cope with change.

‘I want to learn a lot. Everybody is using computers these days, you look stupid when you don’t know how I am ashamed to say that.’ (*Nurse 74, female*)

‘As long as you tell yourself that you don’t want to, like the only problem is when people resist to that to change, but once you accept I don’t think they will be a problem.’ (*Nurse 75, female*)

However, there is recognition that ICT will become part of the health system and the nurses' everyday work: 'I think it's where the world is moving you know' (*Nurse 76, female*). Across all of the clinics there was a consensus that they were too busy to use computers.

'No, we are always busy and there is no time for computers' (*Nurse 76, female*)

There is often reluctance by staff to learn ICT skills because of the workload and other stressors. A nurse suggests that perhaps her inability to use a computer is due to laziness.

'I am computer illiterate, let me say so, maybe laziness.' (*Nurse 92, female*)

A doctor believed the older nurses would never really learn how to use and grasp computers.

'It is the mindset. I just can't see how you could. I can't see how it could ever happen here when they [*the nurses*] don't even use computers at home.' (*Doctor 63, female*)

The doctor explained that the quality of data collected is often poor. The nurses do not get much feedback and they are not using the data. They are just capturing the data to be used at the national level. He explained that this would have to change as an incentive for nurses to want to learn how to use computers and understand that the data that they are inputting is meaningful.

There was an assumption that a computer would solve all of their problems. A nurse said that staff members ‘will embrace it because it’s good instead of going to the libraries go straight to the cell phone and go on Google and get it – without wasting any time’ (*Nurse 79, female*). It was evident that the majority of nurses had little or no experience of ever using a computer.

‘I know nothing about computers and have never done computers.’

(*Nurse 69, female*)

One clinic had a brand new computer, still in its box after several months because the clinical members of staff did not know how to use it. They were waiting for somebody (there were contrasting reports as to who) to set it up.

‘Yes we think so, they are coming to fix it but we are still waiting for

them to come’ (*Nurse 72, female*)

Clinics had not been built with technology in mind. There was not enough space for computers to be kept, with the nurses complaining about the small space. In one instance, the computer was within a storeroom, also used to store patient files, as the kitchen and staff room. It was an overcrowded space, not conducive to working effectively on a computer, especially because there was no room for a chair. It was not connected to a power supply. In clinics with working computers they were not connected to the Internet.

‘The space here is too small. We don’t have a data capturer to use it.

Most of us are not used to computers. I think that is the reason.’ (*Nurse 148, male*)

Computer skills may be transferable to mobile devices such as smartphones, patient monitoring devices, personal digital assistants and tablets. These technologies can then support administration, clinical management to organise or deliver services, for communication between health-workers or between health-workers and patients and for the delivery of primary healthcare services.

Nurses’ future use of computers summary

It was evident that nurses were eager to learn computer skills and realised the benefits of digitising many of their patient registries. They were also openly honest about whether the task would be too daunting and questioned whether a computer would make their work more efficient. In another study, two rural South African hospitals were given advanced computers and software to determine the impact of eHealth on the deprivation of quality healthcare (Zheng & Walsham, 2008). A lack of information literacy meant the health-workers’ agency of freedom to make effective use of the computers was curtailed. This suggests that, even when resources are present, some staff do not have the capability to use them effectively. This can contribute to nurses’ resistance to computers.

Often the nurse in charge of the clinics did not have appropriate computer skills and therefore could not supervise more junior nurses. There was evidence of junior nurses actually teaching the senior nurses. More eHealth leadership has to exist so that staff are well-managed and have adequate ICT training and on-going support.

The CMO for the theme ‘nurses’ use of computers’ follows the theme of web-literacy. This suggests that if a health-worker does not have access to a computer or the necessary skills, they lack the opportunity to improve workload. For example to search for digital guidelines or speed up administration tasks. ‘Motivation’ may increase if nurses see a reduction in time to achieve the same ends when using computers or digital devices to assist with everyday work practices. They have the information to know how to change and the knowledge of how this change will improve work practice. The theory to support this is that of normalisation process theory (May *et al.*, 2007), because if nurses are to attain and use computer skills at work, this process will need to be implemented, embedded and integrated into their work routines over time.

Theme 8: Nurses’ use of computers

C⁸ – clinical primary healthcare setting is low resourced. Health-worker does not have access to a work computer or skills. Health-worker has access to a personal phone, which might be a mobile digital device such as a smartphone or tablet.

M⁸ – information, for example government protocols/guidelines or government app and motivation to use digital device or computer to perform work tasks.

O⁸ – trained in computer skills that can be transferable to other digital devices. Improved reporting of clinic statistics and potentially future electronic patient health records.

It will not work in contexts if the nurses feel more laboured with digital tasks and prefer to continue as normal.

Theme 9: Future use of eHealth and mHealth

Future patient electronic records system

Another example of a future digital health system is that of a patient electronic records system. Some health-workers discussed the use of switching from paper records to an electronic system. The hospital manager claimed that progress is being made but there was no evidence of an electronic system in place.

‘Patient electronic records – we are getting there but it is slow, that is the challenge.’ (*Hospital manager 65, female*)

A provincial policy-maker admitted that patient electronic records in rural South African clinics and district hospitals were not going to be possible, even

though he was in support of the NHI scheme. The NHI will rely on an electronic health information system.

‘There is potential, with electronic taking over paper records but very few institutions will be able to do so.’ (*Provincial policy-maker 101, male*)

Another policy-maker suggested that an electronic system would take ten years to implement nationally.

‘There is nowhere that you are going to find a full electronic system from cradle to grave but components of it are happening. Maybe over the next ten years the dots will be connected.’ (*Provincial policy-maker 98, male*)

The doctors were not convinced that an electronic patient record system would be beneficial.

‘If you can’t get basic healthcare, you can’t get basic equipment, you can’t feed your doctors in theatre more than bread and butter, I am sure that trying to organise a digitalised interlinking computer system, that is maintained and people are trained on, is impossible’. (*Doctor 125, male*)

However, one doctor said that writing paper notes in hospital was part of his job. He had become accustomed to that way of doing things and so changing to digital notes would be difficult.

‘Shew [*a sign of expression*]! To be honest I don’t see that. I think I have just gotten used to the writing but I think it can be introduced but it will have to be in phases, it can’t be all at once, this is comfortable [*referring to paper patient files*].’ (Doctor 67, male)

Other doctors were also sceptical about an electronic system because of the poor power supplies and frequent outages the area experienced. He suggested that having an electronic system, that was not always functional, is not worth it.

‘We will probably have three down days a month. I don’t think you can run an electronic record system with three down days a month – it means that any time you have to do something twice, not that the paper system is faultless, it is horrible it needs to end the duplication of tests and results between different hospitals but I think that doing an electronic record system badly, is not worth it.’ (Doctor 70, male)

Another doctor said when the hospital had previously invested in some computer screens they had been stolen and could envisage the same happening in the future.

‘No not here, I think they invested in some screens for viewing X-rays down in casualty... but they were stolen quite quickly.’ (Doctor 146, male)

A foreign doctor, who had worked in both the UK's NHS (National Health Service) and in the rural hospital, explained her reasons for why an electronic patient record system was unlikely to work.

‘In the UK, only become computerised in the last 5–10 years. I just can’t see how it could ever happen here when you have a completely different group. You might have nurses working here who might have a car, kids in good schools, but they have never used a computer in their life. It is the mindset. I just can’t see how you could.’ (*Doctor 63, female*)

This doctor sensed that the establishment of electronic records would take years and need more staff to make it work.

‘I feel that given the reality of service delivery in this hospital, I can’t foresee it in the next matter of years. I think it will take approaching a decade to be possible and it will never be done on the current staffing levels.’ (*Doctor 70, male*)

Health-workers’ general opinions about the uptake of the eHealth and mHealth policies

Many doctors were sceptical about the future of the government’s eHealth and mHealth policies, which laid the foundations for a future electronic patient records system. A doctor thought that there were too many promises of policies not fulfilled. There would be ‘real problems of roll-out of

expensive technology in rural areas' (*Doctor 70, male*). The doctor also said how little had changed, even though the country had very reasonable and sound policies.

'I am a reasonable fan of Dr Motsoaledi. I think his policies are fantastic. I think like many of the government things, the delivery of them. It is not the policy; it is the inefficiencies and dilutions that occur. Although he comes out with a fantastic eHealth policy, 5–6 years down line – no change.' (*Doctor 70, male*)

In an urban hospital in another city, a doctor experienced an efficient system whereby 'whenever the X-ray was taken it goes online so wherever you are in that province you can access the X-ray on a computer and the same system needs to exist in the rural areas' (*Doctor 125, male*). This suggests that if it is possible in some urban hospitals, it may be an option for rural areas.

None of the nurses had ever heard of the eHealth policy. One nurse said he had but could not give any details.

'I did hear but I don't have enough information about it.' (*Nurse 148, male*)

The clinical associates knew little about the eHealth Strategy.

'I heard about but I don't know if it was implemented yet ... I have not seen any progress.' (*Clinical associate student 127, female*)

An almost retired doctor, who had worked in a government hospital his whole career, thought any eHealth solution would fail.

‘Now you are asking me this! It will fail completely.’ (*Doctor 128, male*)

He was very disapproving and negative of introducing more electronic systems into the health system, possibly because he had a long-invested career as a rural surgeon and was not a technology user. He questioned how electronic health would actually improve service delivery.

‘Even the nurses aren’t educated enough... eHealth is not helping the people from getting sick.’ (*Doctor 125, male*)

A further description of experts and policy-makers’ opinions for the future of digital communication in South Africa is presented in Chapter 7.

The CMO for the theme ‘future use of eHealth and mHealth’ suggests that digital health may be a possibility for both patients and health-workers in rural settings to improve and support the delivery of healthcare. If, for example, patient information is better stored and managed digitally, patient notes can be retrieved in real time. However, there is a general feeling of contempt from health-workers, who will need more convincing about the future of eHealth and mHealth policies. As demonstrated in Research Question 2, the future of diagnostic referrals made via secure digital messaging platforms and apps, often designed by the doctors are viable, if used in a more formalised way with backing and accreditation from the government. The training of nurses in computer literacy to improve laborious

handwritten administration tasks is also possible. This has to become more commonplace before patient electronic health records can exist, as well as routine health information systems. Communication between patients and nurses via mobile phones is also an area of great potential. The mechanism of ‘information’ is key to the future of eHealth and mHealth. For example, information from routine health information systems to access patient electronic records driven by top-down policies.

Theme 9: Future use of eHealth and mHealth

C⁹ – given the current use of mobile phones and computers for health-related purposes among patients and health-workers, there is scope to increase and formalise the trend.

M⁹ – information for use in service delivery and for knowledge.

O⁹ – patient electronic records that can be synced so that both clinics and district hospital can access patient files – quicker retrieval of patient’s clinical information.

This may not work in a context where the challenges of the health system compound the success of eHealth and mHealth and deny the health-workers the opportunity to engage in digital work practices.

Conclusion of Research Question 3

This section has met the initial objective of describing and exploring with patients and health-workers the potential future use of mobile phones within South African primary healthcare clinics. In conclusion, the potential for the

use of mobile phones to enhance primary healthcare delivery is evident and can be supported by mechanisms. The development of this question continues in the final chapter's discussion, where the CMOc theory is refined.




6.8 Summary of Chapter 6

The theoretical framework in Chapter 1 guided the interpretation of results. The results from the realist review were linked to the Vutivi findings. The hypothesis (middle-range theories in the form of the CMOc) from the realist review to support, refute or refine these theories with evidence from the empirical data was adopted. From the Vutivi study themes, evidence was found to both support and refine the original realist review hypotheses. For example, the realist mechanisms supported by high-level theory were applied to each macro-theme. The findings from the realist synthesis have been tested and transferred to interpret the empirical work in different contexts. What was learned in context A (realist review of digital monitoring in LMICs) can be applied to various situations in context B (empirical research on various digital solutions in rural South Africa).

By broadly applying the mechanisms from the 'middle-range theories' in the form of CMOc on the digital monitoring of chronic disease, mechanisms were transferred and interpreted to other areas of mHealth solutions found in the nine macro-themes presented in Chapter 3. The examples of solutions in this

thesis are defined by Labrique *et al.* (2013:168) in Table 28 as: *digital decision-support, client education and behaviour change communication, sensors and point of care diagnostics, provider training and education, work planning and scheduling, supply chain management and provider-to-provider communication*. Each solution has been presented with an example described in this study.

Table 28. Summary of the results themes related to Labrique's taxonomy of eHealth and mHealth solutions, presented in Chapter 6

Macro-theme	Vutivi theme related Labrique's taxonomy of eHealth and mHealth solutions
-Access to health information -Adolescent phone use (informal) -Phones used to support chronic disease management	<div>  <p>Client Education & Behaviour Change Communication</p> </div> <p>Nkateko digital reminders</p>
-Web-literacy of patients and health-workers -Nurses use of computers	<div>  <p>Electronic Decision Support Information, protocols, algorithms, checklists</p> </div> <p>Use of digital resources patients and health-workers</p>
Phones used to support doctor work practices	<div>  <p>Sensors & Point of Care Diagnostics</p> </div> <p>WhatsApp messaging and Vula Mobile</p>

	<div>9 Provider Training & Education</div> <p>The use of digital resources by clinical associate students</p>
Local digital innovation by doctors	<div>8 Provider Work Planning & Scheduling</div> <p>Thumela Mobile (referrals)</p>
Digital solutions to drug stock-outs	<div>11 Supply Chain Management</div> <div>7 Provider-to-Provider Communication User groups, consultation</div> <p>Stop Stock-outs (drugs)</p>

Mechanisms found to cause change in the realist review can have the same effect in examples from the Vutivi empirical study. The links between the findings from the realist review and this empirical study, demonstrate that mechanisms are transferable to different contexts when the pre-existing structures influence a mechanism. Therefore, the framework from the realist review informed these empirical qualitative results. Once the main themes were derived from the analysis, a CMOc for each theme was supported and based on the realist synthesis.

This chapter has helped to understand ‘what works...’ by detailing the CMOc in each theme’s summary. The results have demonstrated that both current and future use of digital technology is evident and viable for both patients and health-workers in this context. Table 29 summarises the key issues found in this chapter.

Table 29. Summary of key issues of improved digital communication, access to information and continuity of care and mains themes supported by CMOc

Key issues in current and future use of eHealth and mHealth
<p><i>Improved Digital Communication</i></p> <ul style="list-style-type: none"> • Poor communication reduced the ability of patients and health-workers to efficiently care or be cared for. • The resource-constrained health system is further hampered by inadequate ambulatory services and a lack of subsidised transport. Stagnant referrals could cause inhibited care often due to the dis-functioning operating system using fixed-line phones. • Point of care diagnosis can be strengthened by the diagnostic capabilities of digital solutions such as using a smartphone to take photographs sent to specialists. Only if the process is regulated using secure messaging platforms. • There was evidence of poor web-literacy of health-workers and patients. <p><i>Themes</i></p> <p>Digital solution to drug stock-outs</p> <p>Phones used to support doctors work practice (Smartphones creating inequity balance)</p> <p>Local digital innovation by doctors</p> <p>Nurses' computer use</p>
<p><i>Access to Information</i></p> <ul style="list-style-type: none"> • Access to health information can be ad hoc and intermittent. • Poor client/patient/community education and knowledge is related to inadequate understanding of illness and late/delayed uptake of care. • Health information is currently acquired from clinics, television, radio, newspapers, community or the Internet. • The utilisation of phones for health is emerging to vary degrees. <p><i>Themes</i></p> <p>Patient education (access to health information)</p> <p>Web-literacy of patients and health-workers</p> <p>Adolescent phone use (informal)</p>
<p><i>Continuity of Care</i></p> <ul style="list-style-type: none"> • Continuity of care can be enhanced through reminder text-messages or calls for appointments and extended to medication reminders and the tracing non-attending patients via mobile phones. <p><i>Themes</i></p> <p>Phones used to support chronic disease management</p>

Poor Management and failure to maintain equipment

- The current mismanagement of hospital resources especially equipment may affect the ability to manage and sustainably maintain digital solutions in the future.
- There was evidence of mismanagement of resources and poor allocation of funds combined with a reactionary attitude towards new technology.

Themes

Future use of eHealth and mHealth

Findings around current and future use of mobile phones and computers can be linked to the challenges faced by health-workers and patients. This can help to understand how digital communication can assist issues, which may arise given the current problems. Considering the health system challenges, emphasised in Chapter 5 as broad context and findings from Chapter 6, a summary discussion will now conclude this results chapter.

6.9 Conclusion of Chapter 6

The current paper patient records need to be better organised and potentially even digitised into electronic patient records. It would need to be a resilient system with an alternative plan for if the electricity fails or the system breaks down. Electronic patient records are one of the aims of the NHI and without a health information system in place the policy will never be realised. However, most of the doctors were very uncertain of it ever taking off, especially because of issues of theft of phone lines and a reactionary staff mindset. The mainstreaming of mobile health services ‘hinges on clinical buy-in’ (Taylor *et al.*, 2015:326). Where barriers to successful

implementation exist, clinicians can lose faith in using technology to perform tasks traditionally delivered in person. Logistical issues are the main cause of drug stock-outs, rather than an actual shortage of drugs. A computerised automatic ordering system used by nurses and hospital pharmacists can replace hand-written faxes. This should make the Stop Stock-outs campaign redundant, which is their aim. It was evident that health-workers understood the benefit of using technology to enhance their everyday work practices. However, they are realistic about whether technology can make improvements.

Results suggest the need for a secure mobile messaging for medical chat, digital lab results and adherence monitoring, to increase access. Health-workers can perform quicker and more accurate referrals. Health-workers will need to understand why they are using the technology and how it helps their routine work and patients' needs. More formal adaptations need to build on the existing use of these digital forms of communication. Of particular significance, is how to improve the processes with which to remind and follow-up patients. Also to understand and assist with the difficulties they face in obtaining access and information and the means by which this is communicated. Patients are actively seeking digital health information, in addition to what they learn from the clinics and family. Specific and evidence-based web sources can become a more formal platform to engage with

specific health knowledge to enhance understanding and increase access. There was evidence of patients communicating with private doctors and indigenous traditional healers via their phones to receive advice. This seemed a viable option, whereas communicating with nurses in the public health system was less accessible.

Digital health solutions to support the health system will not change the disease burden but may improve people's education in both prevention and management as a result of greater channels of communication. Challenges within the primary care settings and district hospitals could jeopardise the successful implementation and value of digital communication systems.

Tackling the identified problems in the South African health settings is likely to require the strengthening of clinical primary and district-level services and can in some instances be supported by digital solutions. These can enable better quality communication and improve access to healthcare. For nurses and doctors, this may result in more efficient practices and consequently in more productive time and, potentially better outcomes and quality of care. Although investment into digital health solutions is likely to improve communication, factors such as poor management and the failure to maintain equipment can curtail the benefits of enhanced communication and waste financial valuable resources. Issues of poor supervision need to be resolved

because with the mounting use of digital systems, supervisors will also need to support the use of these technologies. The healthcare staff must understand that digital solutions will not remedy everything but will take time to improve work practice.

6.10 Strengths and limitations of the Vutivi results

A discussion of the strengths and limitations from the results chapter is now presented. The micro limitations presented here are specific to the results presented in Chapter 6.

Strengths of qualitative results from the study site

This chapter has synthesised data from a rural area to understand end-users' digital technology behaviours, which will help in the development of future mHealth initiatives.

A strength of interviewing the participants during the Nkateko trial meant that they were currently receiving the reminder phone calls, so the intervention was fresh in their memories. Most people did not have difficulty in recalling details of their experiences. It was very useful to get data from participants receiving an mHealth intervention as this supports findings from Vutivi patients, who prospectively said that they would like digital reminders.

Limitations of results from the study site

Firstly, the analysis from the Nkateko trial was carried out independent of any knowledge of the trial results. The trial was still on-going at the time of analysis and their results have not been published at the time of writing. Arguably, the interviews with the trial control group should have also been conducted to ascertain how they would feel about receiving a reminder message/phone call from a LHW. This was unnecessary because their responses may have been similar to those of the Vutivi participants, who were not participating in a trial nor receiving any type of mHealth intervention.

There was always a concern of ‘social desirability’ of response (Neeley & Cronley, 2004:432); even though it was explained to the participants that the researcher was independent of the Nkateko team. Patients may have told the fieldworker that they appreciated the reminder phone message.

Since patients were waiting in the queue to see the nurse, we were wary of the length of the interviews. Short interviews meant that little time was available for rapport to be built with the participants, but trust did not seem to be an issue.

To conduct interviews in more than one district hospital was not time feasible. However, it was felt that the same issues that arose would have existed in the other two hospitals within the area.

A potential limitation of this study was not interviewing several participant groups. For example, women with babies aged four weeks and over would have been useful to gain perspectives of new mothers and their phone use during this period.

Ethics was only requested for participants 18 years old and above. It would have been useful to interview a cohort of teenagers who were active social media and Internet-users and who assisted their older relations with their mobile phones. However, we did interview many school-going 18-year-olds and felt that their technology use would not be significantly different from 14–18 year olds.

Patients with acute conditions were not interviewed, although it would have been feasible to recruit them from the acute condition queue. Acute patients were, more often than not, one-off clients seeking healthcare for influenza or other seasonal outbreaks. It would have been useful to hear how phones could be used for acute primary health. For example, when a person has a headache and how they could use digital technology to aid healthcare without consulting a nurse in very mild cases.

Ambulance workers and paramedics could have been interviewed since they communicate with nurses, doctors and hospital switchboards whilst

travelling. The use of mHealth for their work role would have been interesting to explore and requires investigation.

Although patients were interviewed in isolation, afterwards they returned to the queue. Here they could talk to other chronic disease patients, who would potentially be interviewed later. This may have caused bias, if the person already interviewed had discussed what they told us in the interview, influencing the other person's responses. There was no evidence for this happening. There were a few participants' friends and relations who also took part, but they were usually interviewed separately.

Also, recruiting directly from the queue meant that, often, participants had a short period of time to consider whether they wanted to be involved. They had time to read the participant information sheet and digest what the study was about from the nurse and fieldworker introductions.

The Dictaphone frightened some patients, so explanation was necessary to assure the person who had already consented to being audio-recorded that only the fieldworker and researcher would listen to the interview.

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Following on from the first two results chapters, Chapter 7 now presents the final results chapter: the landscape of eHealth and mHealth in South Africa. Dialogues with policy-makers and experts about relevant policies, enablers and barriers to technology uptake and the opinions of these stakeholders are debated. A health systems theory framework to guide the interpretation of findings is presented.

Chapter 7



Photo 22. Airtime seller in the town

Chapter 7: Results – Policy and national issues around eHealth and mHealth in South Africa

7.1 Introduction and structure of Chapter 7

Chapters 5 and 6 discussed Research Questions 2 and 3: the current and future use of digital health technology for patients and health-workers. The chapters focused on consolidating theory from the realist review and establishing further theory from the Vutivi primary research into CMOc. This chapter seeks to understand the digital communication technology landscape in South Africa, from the point of view of policy-makers and eHealth and mHealth experts in answer to Research Question 4.

Research Question 4.

What are the government stewardship, organisational, technological and financial enablers and barriers to the use of digital communication for the delivery of primary healthcare in rural South Africa?

Findings in this chapter are from beyond the field site case study and are from the overall South African case study on policy. Exploration of the links between the perspectives of patients and health-workers on the ground at the micro- and meso-levels (from Chapters 5 and 6) are compared with perspectives of top-down macro-level policy-makers and eHealth and

mHealth experts. They work as the developers, implementers and decision-makers in the health system. This chapter contributes to the understanding of enabling factors, as opportunities and of barriers, as challenges or constraints, to the uptake of eHealth and mHealth within rural public health facilities. This was accomplished by undertaking in-depth interviews with government policy-makers and eHealth and mHealth experts (hereafter referred to as ‘experts’) whose work is relevant to the future development, implementation and evaluation of digital communication technology in South Africa.

The following will be addressed: *Landscape/context of eHealth and mHealth in South Africa and the different stakeholders’ role in the formation of the digital communication ecosystem*. These top-down findings are essential in supporting the synthesis from the field site case study. The chapter is structured by a brief overview of the types of policy-makers’ and experts’ jobs to understand their opinions on DOH digital programmes. Policies relevant to eHealth and mHealth in South Africa and non-government initiated mHealth pilots are then introduced. A comprehensive explanation of the current digital landscape is presented, using four health system dimensions with barriers and enablers for scale-up. The chapter culminates in a theoretical framework to critique the findings from all three results chapters.

7.2 General context of the eHealth and mHealth ecosystem in South Africa

Policy-makers' and eHealth and mHealth experts' work roles

This section describes the job types of policy-makers and experts interviewed. This was integral to the content covered in each interview. This section gives context for understanding their opinions around digital communication in South Africa later in the chapter. Those interviewed, represented the broad-ranging network of 'players' currently involved in the country's eHealth and mHealth ecosystem. This network of players comprised of four groups described the Groupe Speciale Mobile Association (GSMA) as the *payer, producer, provider and consumer* (Friderichs, 2014), as illustrated in Figure 23. To ensure participant anonymity, their organisations' names have been redacted.

The provincial and national policy-makers were 'technocrats', responsible for writing policy. They were employed within a government department rather than as a political party member for the ruling party, the African National Congress Party (ANC). Those at the district level of the DOH were considered the 'decision-makers'.

The chief mHealth advisor to the government was on secondment from a South African-based NGO and also one of the pioneers of the MomConnect Programme.

‘I have been placed in the NDOH as a technical assistant to the Director General for Maternal Health, TB and HIV. I am involved in reviewing policy and giving him advice, which he sometimes takes and sometimes does not, about different aspects related to his three areas and related to primary healthcare in general.’ (*National policy-maker 98, male*)

A National DOH policy-maker described herself as a custodian of eHealth.

‘I am the Director for National Health Information Systems ... it is quite a large portfolio. We manage the District Health Information System, which is the main health monitoring system.’ (*National policy-maker 99, female*)

Experts were usually senior members of their departments within their organisation. Due to the nature of eHealth and mHealth being in its infancy, many participants knew one another and were familiar with each other’s work. This is why snowball sampling proved very effective. Experts included a range of diverse players from parastatal companies (controlled or owned wholly or partly by the government), research institutions and private organisations (Table 30).

Table 30. Demographics of experts’ organisation types

Organisation type	Total number	Example
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NGO	5	Advocacy groups, mHealth project implementers, consultants
Parastatal	4	Public/private partnerships delivering healthcare or research organisations
Academic/Research	4	Affiliated associations of institutions
Private	12	Mobile operators, software developers, Telemedicine providers, social media platforms, engineer

Many of the experts worked closely with the policy-makers and several were part of the NDOH mHealth Task Team, principally for the development of MomConnect.

Policy environment in South Africa: documentary analysis of policies described in the background narrative review

This section begins with a documentary analysis on current government policy pertaining to eHealth and mHealth, following their introduction in Chapter 2. This policy context is important to situate the findings to Research Question 4. There is a supportive policy environment in South Africa, demonstrated through the publication of the eHealth and mHealth Strategies, the mHealth Task Team and the eHealth advisory committee.

Policy development: conception of the eHealth Strategy

The Scottish eHealth policy was used as a guide to the draft South African policy as the WHO's (2011) 'National eHealth Strategy Toolkit' was not yet published. An expert suggested that the Strategy had been very 'well-written

because it was written by industry rather than government’ (*Expert 104, male*). However, once the policy was published, a vacuum existed in terms of its implementation. No one was leading its adoption and those driving it became surplus to requirements within government and their organisations.

‘I think that everyone was quite happy with that document as there was a lot of momentum about it. Then it was very much a case of ... we have got the Strategy now what? There wasn’t really a project manager or key champion in the department to get it going. So in many ways it’s in slow motion.’ (*Expert 103, female*)

The author explained that, because of its slow start, the Strategy is now in need of revision because a lot of the deadlines have passed, ‘so we need to revise the implementation Roadmap. In 2016 we will start working on a new one’ (*Expert 103, female*). The revision focuses on better implementation of eHealth initiatives.

‘Strategies don’t need revision very often, it is the implementation plans that might need to be revised.’ (*National policy-maker 105, male*)

This suggests that the South African eHealth landscape needs more time and investment. An mHealth Task Team member said that the building blocks or foundations for a successful policy were already in place. This should allow the country to scale-up eHealth programmes, such as providing electronic health records containing good quality data. He reiterated that there needs to

be an emphasis on governance and further investment and support in moving from paper-based to electronic systems.

‘The eHealth Strategy is a very good starting place. The important thing is we need to get the foundations set up, do them well and in an interoperable fashion that will scale and allow interlink-ups with the whole country. Electronic health records but also health information on a national level that has good levels of data quality and is generally useful, correct and complete and does not have all of these errors and gaps in place.’ (*Expert 108, male*)

The expert believed that in order for eHealth to flourish, the right environment must be created. However, health-workers are not always computer literate and this can only change through training and improved management.

‘The expectations to put a system in place, where you may have staff who are not particularly computer literate is scary at best, so there needs to be a whole change management programme that goes with this with concerted levels of training.’ (*Expert 108, male*)

Successful implementation of other national policies relies on the success of the eHealth Strategy. The National Health Insurance (NHI) scheme will struggle to come into fruition without effective eHealth. It promotes a good starting place for change to begin.

‘Start investing in the right way to scale it up. The eHealth Strategy does give a starting place for that to happen.’ (*Expert 108, male*)

Moving from policy rhetoric to actual rigorous implementation is where the stumbling block develops.

Government budget for eHealth and mHealth in South Africa

Financial constraints are a major barrier to successful implementation. Leon *et al.* (2012:9) argue that the uncertain funding streams could ‘threaten the sustainability of large scale mainstream mHealth projects’. As with most countries governments, the NDOH has a long budget cycle and is very bureaucratic, taking a long time to make decisions about where money should be spent. The policy-makers interviewed did not want to state the eHealth budget, largely because ‘the proportion spent on eHealth is not exactly known, but extremely small’ (*Provincial policy-maker 101, male*). A policy-maker suggested she found the money by ‘digging it out from other projects that are heavily leveraged, so I borrow resources and use that to help push my Strategies’ (*National policy-maker 99, female*). An expert, who agreed that external donations are currently funding eHealth and mHealth programme, supported this.

‘In South Africa, the NDOH are not spending their own money, they are spending donors’ money. They ask the USAID to fund their start-up projects around mHealth with the long-term aim of getting it into the national budget.’ (*Expert 106, male*)

Budgets will increase with government commitment, if priority is given to eHealth and mHealth. Foreign government aid allows the government to start deploying digital communication systems for the priority health areas.

‘We have a centralised cluster budget. I have got a very good relationship with the donor community. That is the way I get the work done.’ (*National policy-maker 99, female*)

A policy-maker said that implementation is difficult because of budget constraints.

‘It is all well and good having a successful policy but if you don’t have an allocated budget then you are struggling. So there are very small amounts coming from the department in general. Not something that has been put as a major priority in my view.’ (*Expert 108, male*)

Policy-makers voiced that ‘currently at the moment, we do not have enough capital resources and you know when you do not have money, it is just difficult to implement the eHealth Strategy’ (*National policy-maker 102, male*). There was a consensus by policy-makers and experts that, despite the government’s efforts to propel the strategies forward through a donor-funded ‘aid for development’ model, this can be unpredictable. A larger treasury-funded budget is necessary.

Comparison of the eHealth and mHealth budgets between provinces

eHealth and mHealth budgets differed between provinces. A policy-maker from a province run by the main political opposition party to the ANC, the Democratic Alliance (DA), said that her province was the most mature eHealth province: ‘our province has an allocated budget for ICT’ (*Provincial policy-maker 107, female*). Provincial budgets are managed differently. Each province obtains money from the National Treasury and can decide how to allocate a percentage to ICT. She explained that, in her province, information was still manually collected in clinics but an electronic system was on the horizon.

‘The hospitals are established but the primary healthcare are really starting to move in that direction, we do have quite a good system but it take a while to run.’ (*Provincial policy 107, Maker female*)

Relevant policy: interoperability standards

A related policy that supports eHealth and mHealth implementation is the National Health Normative Framework (NDOH, 2014a). This contains the interoperability standards that any digital communication programme must adhere to. The purpose of the interoperability framework is to set standards for information-sharing between clinics, hospital, pharmacies and laboratories. The development of an interoperable architecture defines how eHealth solutions across all levels of healthcare will interoperate to support

person-centric continuity of care. One of the experts who helped to devise these standards explained its importance for the future of information-exchange.

‘It outlines the over-arching architecture. Every eHealth activity should fall and comply within those guidelines and the work that has to be done going forward is to localise those standards and putting some infrastructure in place. So we can have a health information exchange and electronic health records.’ (*Expert 108, male*)

The expert said that everyone must adhere to these standards because it mandates what infrastructure is needed.

‘It includes any patient data; it gives standards for electronic health records, for imagining, storing information. It really outlines all the different standards that need to be used for the future.’ (*Expert 104, male*)

There should be a trickle-down effect of using the standards through to the provincial and district levels so that solutions ‘comply with the standards without stifling innovation’ (*Expert 103, female*).

Fragmentation of health information systems

The second part of the interoperability report is an assessment of the patient-based information system. Experts discussed the fragmented systems in human resources and finance. There are around 54 different information

systems identified in the country. Provinces have different systems in place that work in silos and are not interoperable. Therefore, a moratorium was placed on the use of new information systems.

‘This will determine whether we will lift the moratorium ... start moving forward with the interoperability and this clears the road for mHealth and eHealth.’ (*National policy-maker 99, female*)

All existing health information systems, including pharmaceutical, are now issued a certificate of compliance if their system meets the minimum interoperability requirements. Historically, there has been considerable irregularity around the buying of patient-based information systems. There has been no shortage of people wanting to ‘implement electronic means of data capture and electronic records’ (*Expert 108, male*). A policy-maker described the situation as chaotic because before now there has not been an interoperability framework to guide systems.

eHealth and mHealth projects in South Africa

It is largely unknown how many eHealth and mHealth programmes are in progress within South Africa. Although the GSMA (2013:12) published a figure of 83 live mHealth projects, one expert described this as ‘a laundry list of projects’ (*Expert 166, male*). Most projects never exit the pilot stage because of costing issues and poor evaluations. The head of a NGO described the lack of projects at scale.

‘While there is huge amount of buzz around mHealth, there is actually desperately few that have gone to scale. Less than ten that I could mention.’ (*Expert 106, male*)

A senior policy-maker was cautious of pilots.

‘I guess we have this proliferation of pilot projects that are not really sustainable. What we really need to see is projects moving from a pilot phase to a sustainable stage.’ (*National policy-maker 102, male*)

The fragmentation and duplication of effort was repeatedly discussed. An expert suggested that projects must be organised and consolidated in a central way.

‘Everyone is running around doing their own thing. We need to see how to bring things to scale with defined health outcomes being measured and by providing better services and considering costs. Otherwise it will continue to be uncoordinated.’ (*Expert 108, male*)

In summary, there is little control or regulation of pilot programmes. Across South Africa, they are often uncoordinated and do not align with the government’s health priorities.

The risk associated with mHealth projects

A lack of evidence creates risk for those willing to invest in eHealth and mHealth. This was a comment repeatedly made by stakeholders from all parts of the ecosystem.

‘A lot of buzz and interest but for serious health decision makers, it is still desperately risky.’ (*Expert 106, male*)

A senior member of the DOH described the risky processes of new mHealth proposals.

‘The DOH is a huge bureaucracy in South Africa. If you are trying to get a policy-maker to sign something off, they just want to know: “Is it safe? Does it work? What does it cost? What will be the impact on the health system?” If you can not answer those questions then they are not really interested.’ (*Expert 106, male*)

An expert from an NGO said, ‘we need to move away from mHealth being a buzz-word to actually being a standard health system thing, that could be rolled-out at scale and as yet desperately few have done that’ (*Expert 106, male*). People lack confidence in knowing whether mHealth will actually work until it becomes normalised and no longer known as ‘mHealth’ because digital health is just the norm.

‘mHealth as a term is not proven yet. We don’t know what works and what doesn’t. mHealth as a term is going to die, hopefully in ten years. 10 per cent of projects that work, are going to be so useful and go to scale. It is not “mHealth” anymore it is just “health”.’ (*Expert 106, male*)

The NGO expert said DOH policy-makers must understand what mHealth actually means and does.

‘Currently mHealth almost doesn’t mean anything. mHealth is not a health issue. No one gets better by receiving an SMS.’ (*Expert 106, male*)

A stakeholder discussed how innovation often leads to failure.

‘Some new technology, anything new is usually something that people don’t like or takes a long time to convince people that they want to use it – people are resistant to change. The health system in South Africa is particular resistant to change.’ (*Expert 122, male*)

He believed that the government understands the complexities of digital communication systems.

‘It is not just about successfully giving a clinic a new computer but moving from a non-technology savvy nurse to one who learns, understands, why she is using a computer in comparison to paper-based methods, and makes it a routine functional part of her working day.’ (*Expert 122, male*)

More incremental steps are needed for mHealth to move to scale. A policy-maker suggested that, sometimes for fear of keeping a project in pilot stage, it is taken to scale too soon. It is then criticised when it fails.

‘Often these decisions to scale projects are based on hope and political aspirations. We want this to work and we want it to work so much that, we don’t want to have a little pilot project, so we try to take it to scale.’ (*Expert 166, male*)

A national policy-maker felt that ‘people are resistant to change especially technology. You can roll-out as many wonderful things as you want to the clinicians, clientele – your visitors to the facility, but they may feel uncomfortable using it’ (*National policy-maker 99, female*). An understanding of the end-user is crucial.

These examples suggest that the field of eHealth and mHealth in South Africa is still considered a ‘risk’ by many. It will take time for digital solutions to be normalised within the health system.

Private eHealth and mHealth initiatives

mHealth initiatives run by the private sector were evident, all with the scope to be adopted by government.

Telemedicine projects

Currently there are no official telemedicine projects at scale, partly because of ethical concerns driven by the Health Professionals Council of South Africa (HPCSA).

‘If someone is giving advice or advising treatment over a distance, it is not face-to-face and it is not the original doctor but someone else, then there is a whole lot of issues about accountability.’ (*Expert 103, female*)

One of the strategic priorities in the eHealth Strategy is stakeholder engagement: effective collaboration between stakeholder groups such as the South African Telemedicine Association. The Telemedicine policy only exists in draft form.

‘According to the HPCSA, a patient can not present themselves to the specialist alone, there has to be another health professional present with them like a doctor or nurse.’ (*Expert 109, male*)

Another reason for the poor uptake of telemedicine is poor legislation around privacy issues.

‘The reason that telemedicine crashed and burned is because the HPCSA had a field day with us; there is no legislation currently for eHealth in the country.’ (*National policy-maker 99, female*)

The CEO of a telemedicine company developed a workstation, which the mobile provider MTN is rolling-out in 100 clinics. The system allows a health practitioner to upload ECG graphs and send these images between facilities. Specialists do remote consultations in a central office located in an urban area, with a rural nurse sitting remotely with the patient. The connection is through a proxy, complicating the connectivity. ‘It was not sufficient for the quality of pictures that came through ... these are the stumbling blocks of telemedicine services’ (*Expert 109, male*). While it was a useful solution in curbing the transportation of patients for referrals, to save money and time, the videoconference was hampered by poor broadband speeds.

‘This would save costs for the DOH because the transport plus the manpower of driving the patient to the hospital.’ (*Expert 109, male*)

The expert said that the telemedicine services could be extended for healthcare use in prisons.

‘There are discussions with Department of Correctional Services to implement this telemedicine in prisons, so prisoners are not taken out of prison to seek medical care at risk of them escaping.’ (*Expert 109, male*)

Future government telemedicine services might reduce congestion in tertiary hospitals by decreasing unnecessary referrals. There are many issues that firstly need to be resolved before this becomes one of the pinnacles of successful eHealth.

Mobile network providers’ mHealth projects

Two of the largest independent South African mobile communications companies were interviewed to discuss their existing mHealth projects. Several of the projects were deployed with government-backing but were small in scale.

‘We deployed 300 devices to CHWs to enable them to go around to rural areas and to collect information from the primary healthcare.’ (*Expert 110, female*)

This is an example of moving from paper towards patient electronic records by gathering digital household records. Another project used SIM cards in refrigerators to monitor the temperature of medical stock during power cuts. Mobile providers are offering solutions for the government's health system challenges.

‘We meet with the DOH, maybe they say one of issues is we are losing a lot of stock because of the temperatures. We say we have the technologies that could solve that. It's enabling technology to create solutions.’ (*Expert 110, female*)

They were questioned about the unaffordability of airtime and data for many rural people, despite the rise in smartphone ownership. The largest mobile network explained that cheaper data services could only be realised when more people start to buy data and thus increase demand. There also needs to be greater competition between networks offering competitive data prices. For now this market is still in its infancy.

‘For people to understand data they have to understand the application and what it means to them.’ (*Expert 110, female*)

Investment into 3G connectivity in the rural areas will only increase if there is client demand.

Digital providers' contribution to the mHealth field

Digital providers who design software platforms for NGOs, government and other companies to buy and use within the health domain and beyond were interviewed.

‘We have seen that technology itself can be a major enabler of social development so we are providing an enterprise type solution to provide an affordable model.’ (*Expert 112, male*)

Currently, one of the digital providers does not work with the NDOH because of the government’s inefficiency.

‘Working with government involves a lot of time, lobbying and politics.’ (*Expert 113, male*)

Instead, their clients are NGOs, who are then better suited to have conversations with government.

‘If they think our technology is a good fit and have that dialogue.’
(*Expert 113, male*)

Feature phones were described ‘as quite a dying breed’ (*Expert 112, male*), since affordable entry-level smartphone phones are now on the market. Phones are no longer used as data-collection tools but also to allow health-workers to make decisions. An expert said that it is not ‘just about collecting the data efficiently through digital means but then knowing what to do with the data’ (*Expert 113, male*). He defined the issues on the ground as often being technology-related.

‘Technology is the most understood part and probably the most easy part to get straightforward but when that technology hits the ground in different locations, different cultural problems and languages and now that is where a lot of our focus is.’ (*Expert 113, male*)

Societies with multiple languages and dialects creates challenges for scaling-up mHealth interventions.

Social networks’ mHealth projects

The CEO of a widely-used South African social media platform described their messaging services as similar to WhatsApp.

‘You can have discussions with your friends and group discussions. It works with all types of phones but majority of our audience have basic phones. You don’t have to have a smart phone for them to access good content.’ (*Expert 114, male*)

Before MomConnect was launched, they were already delivering a pregnancy-related health messaging service.

‘I guess in some respects they are pretty similar to MomConnect. We just started it long ago. So the whole idea is to align it with the woman in her pregnancy, so they get information at most relevant time.’ (*Expert 114, male*)

Their target audience are social network-users over text-message-users.

‘SMS is a one way medium, people do not tend to reply and the level of engagement you get from someone on a SMS is much lower.’

(Expert 114, male)

In summary, examples of mHealth projects by the different partner groups have the potential to be adopted by the NDOH. These groups are represented in the landscape diagram to follow. The eHealth and mHealth context set out in terms of the various policies and programmes by non-governmental organisations represents a suitable foundation to scale-up digital health services.

7.3 Landscape of eHealth and mHealth in South Africa

To further understand the eHealth and mHealth ecosystem in South Africa, a visual diagram illustrating the payers, producers, providers and consumers is presented as a critique of the current digital health landscape (Figure 23).

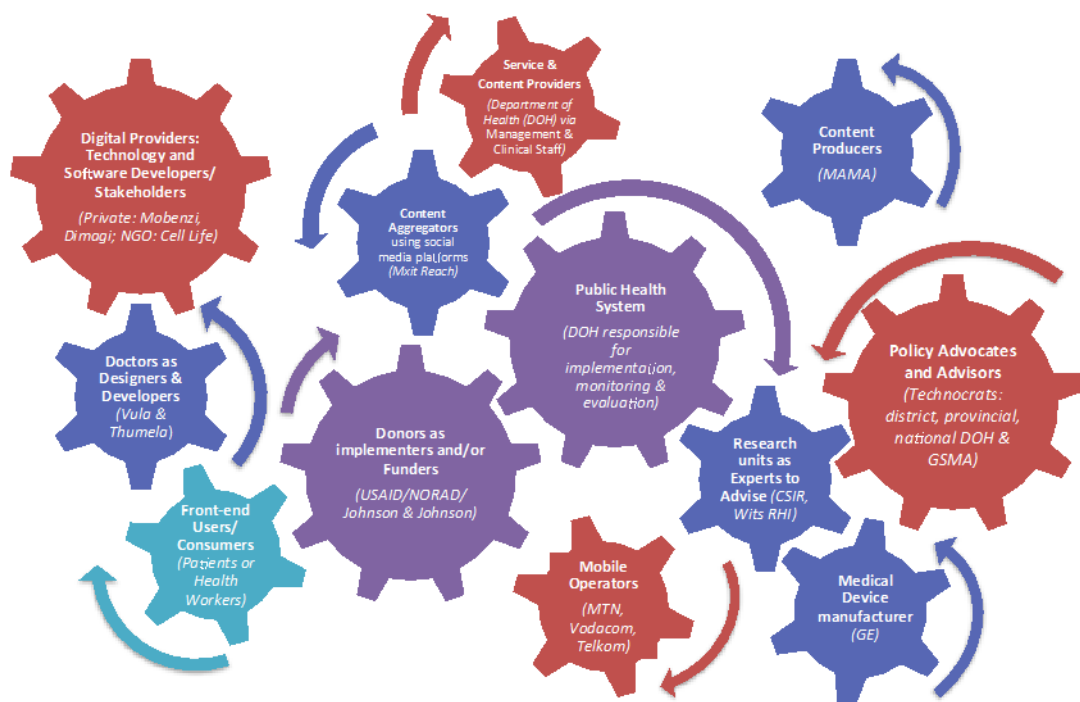


Figure 23. Vutivi eHealth and mHealth landscape in South Africa, illustrating the payers (purple), producers (blue), providers (red) and consumers (turquoise)

The cogs represent the different partner groups interviewed and involved in this landscape. As with any ecosystem, all groups must play their role for the cogs to turn and operate. For example, the interactions between policy advocates, digital providers and front end-users are dependent on each other. Using Vula Mobile as an example the blue cogs represent the producers of the mHealth programme or platform – the doctors who have developed the mHealth solution, such as the eye app. Followed by the providers (in red), who support the adoption of the programme. This includes the mobile

network operators, who provide mobile reception (so the CHWs can send the image to the specialist). Following this, the purple cogs – the payers, such as the DOH who is responsible for funding the programme (and supporting its adoption). Finally, the consumers, the patients or health-workers, in the turquoise cogs, are the end-users of the digital solution (uptake by CHWs to improve remote patient diagnosis). Each play a role within the ecosystem and affect each other's success.

The purpose of this diagram is to help formulate where the country currently is, and what could possibly work in the future. If this is the current landscape needed for the ecosystem to exist, where are the gaps and which groups can form partnerships with the DOH? The diagram can also be used further to portray how the government can optimise the different groups by working with them to create digital solutions. This could ultimately help to improve the service delivery of the country's public health system, with the end goal of improved patient outcomes. The diagram was also useful to inform the final recommendations detailed in the discussion chapter.

Since designing Figure 23, the South African NDOH has produced its own high-level overview, the mHealth Stakeholder Framework (Figure 24), detailed in their mHealth Strategy. The NDOH has included the mobile network operator's regulator called the Independent Communications Authority of South Africa (ICASA), and wireless application service

providers called the State Information Technology Agency (SITA), none of whom were interviewed in this study. However, the NDOH's overview does not account for research institutions, patients and health-workers, donor countries and parastatal companies, though the Department of Communication (DOC) and schools are included.

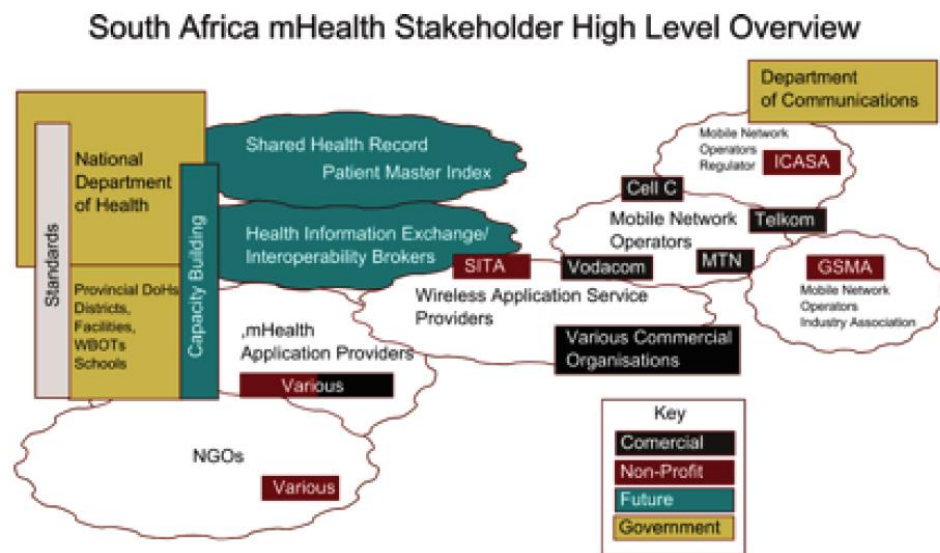


Figure 24. South Africa mHealth stakeholder high-level overview* (NDOH, 2015a)

**The quality of the original image is as poor as produced in the policy document*

In addition to the government's overview, Wilson *et al.* (2014:16) produced a hexagon, with patients at the centre surrounded by the key actors (Figure 25).

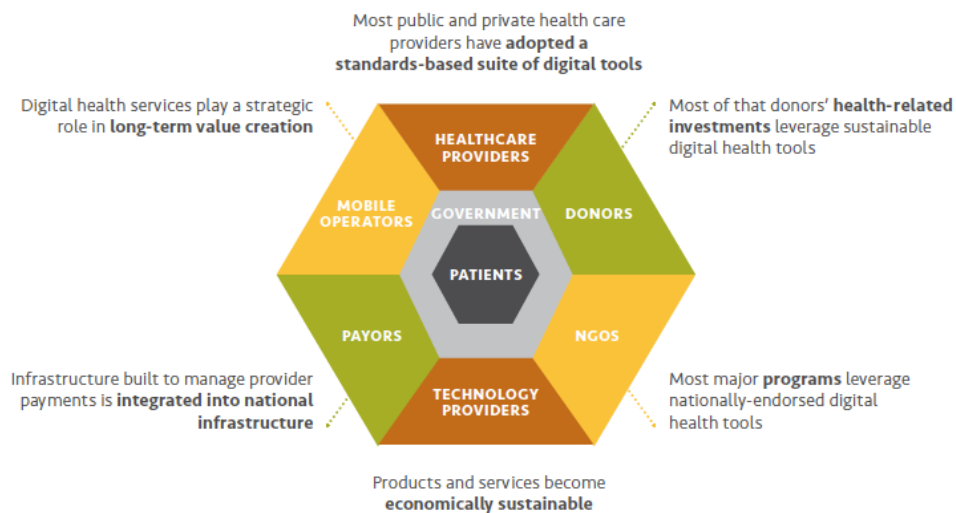


Figure 25. Hexagon to show institutionalisation with different key actors with the patient at the centre when moving mHealth projects to scale (Wilson, 2014:16)

This hexagon does not adequately account for all of the players in the implementation chain. Not only does the Vutivi cog diagram extend these other diagrams, it may also be useful to eHealth and mHealth implementers to consider, when they are designing future programmes.

Adoption, uptake and implementation of government eHealth and mHealth programmes

There has been evidence of the NDOH starting to run pilots and programmes directed towards the development of the NHI scheme. Evidence of eHealth and mHealth policy implementation has been through several initiatives: the Ideal Clinic, District Health Information System, Ward-Based Outreach Teams and MomConnect. Support for eHealth and mHealth initiatives stem from the understanding that they ‘will improve quality of care and improve

health outcomes... by bridging technology' (*National policy-maker 100, male*). Health is not just the DOH's responsibility; it must be a collaboration between government departments 'we must pull all sectors together by putting "Health in all Policies"' (*National policy-maker 115, male*). Policy-makers felt that mHealth was worth investing in because, 'we think we need to take services to people and not just to people come to the services that we provide as a department.' (*National policy-maker 105, male*)




7.4 The adaption of the four health system dimensions from the government's 'Health Systems Framework' in relation to eHealth and mHealth

Leon's *et al.* (2012) 'Health Systems Framework' was applied to facilitate the systematic appraisal and critical analysis of the challenges to scaling up digital communication systems in South Africa for patients and health-workers.

The South African 'national ministry of health is increasingly taking a stewardship role as part of a renewed focus on improving health information systems' (Leon *et al.*, 2012:8). The examples described previously, illustrate evidence for this claim under the four health system dimensions as proposed by government for the use of eHealth and mHealth: *government stewardship and organisation, technological and financial systems*. Leon's *et al.* (2012:5)

framework for decision-making was adopted by the NDOH in their mHealth Strategy for guidance in applying a health systems perspective to appraise the challenges of scaling up mHealth solutions. This framework is updated and extended in this chapter using evidence from the Vutivi study. The Health Systems Framework is applied to current examples of government programmes, addressed under the most relevant dimension. Each dimension will be illustrated using current eHealth and mHealth examples, as in Table 31.

Table 31. Health systems dimension with example government eHealth and mHealth solutions and the related taxonomy

Dimension	Vutivi example related to the eHealth and mHealth solution from Labrique's taxonomy
Government Stewardship	<div>  Electronic Health Records </div> <div>Web-based DHIS</div>
Organisational and Technological Systems	<div>  Data collection & Reporting </div> <div>CHW using mobile phone to collect household data</div>
Financial System	<div>  Client Education & Behaviour Change Communication </div> <div>The MomConnect programme</div>

	<div>3 Registries / Vital Events</div>
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Government Stewardship: strategic leadership and learning environment

Is there a policy environment supportive of mHealth?

‘Sustainability of evidence-informed policy-making, requires strengthening institutional capacity, as well as understanding and addressing the political environment... particularly the incentives facing policy-makers that support the use of evidence in policy cycles’ (Hawkes *et al.*, 2015:1).

Stewardship includes long-term commitment, identifying sustainable funding sources and creating partnerships with NGOs and the private sector to assist with future implementation (WHO, 2011). There is a policy environment supportive of mHealth under the strategic leadership of the Minister of Health, apparent in the MomConnect programme. The evaluation of MomConnect will extend the evidence of mHealth that should in turn influence policy and future practice. The formation of a Task Team for the initiation and development of MomConnect, involved more external experts than members of the NDOH. The professionalism of how MomConnect was deployed, marketed and delivered nationally is testament to leadership of the Directorate of Maternal Health. He successfully leveraged private and public

partners from the inception. However, it cannot be regarded as a mHealth success story until the evaluation results are published and the technical infrastructure has been tested (Seebregts *et al.*, 2016:125). The MomConnect programme is further analysed under ‘financial systems’.

Another example of strategic leadership is the handling of the District Health Information System (DHIS) and the moratorium placed on all disparate systems to ensure one national interoperable system. The NDOH has a clear vision of how it wants to use the DHIS.

District Health Information System (DHIS) as evidence for government stewardship

The NDOH database called the DHIS is a platform that makes use of aggregated and anonymous routine data. The current DHIS relies on data capturers at clinics to record vital statistics from a range of indicators, such as TB results. This system will be extended to include patients’ electronic health records as part of the future NHI. The emergence of new technological platforms, such as a web-based DHIS, is an example of the direction that leadership in the health information field is heading. A policy-maker said that it is ‘an information management system for health information at point of service, mainly for health facilities’ (*Provincial policy-maker 101, male*). He explained that the data flows from district level to provincial and then to national. A policy-maker working on the DHIS described its complexity as

‘another whole messy convoluted circus’ (*National policy-maker 99, female*).

Over time, the quality of the data will be improved by infrastructure and human resource developments. It was evident that there are funding concerns over the DHIS.

‘We don’t have enough money to run DHIS so sometimes you use donor funding to ensure that it is sustained. DFID [*Department for International Development, UK*] also used to sponsor us but that fizzled out from Europe Union.’ (*National policy-maker 99, female*)

Collection and quality of DHIS data

The NDOH’s vision is to improve quality of care and health outcomes by using the technology to assist in turning data into useful information.

‘Turn it into intelligence, so we can make more informed decisions because we sit on mines of data and we sometimes don’t use the data. All of these attempts to make sure we have and improve quality of life and services.’ (*Provincial policy-maker 118, female*)

The DHIS does not run in real time. There is a lag time of up to six-months between when data is collected and entered. The quality of the data recorded by clinics has to improve.

‘There needs to be greater data validation and verification of the quality of data.’ (*National policy-maker 116, male*)

Another expert suggested that poor quality data is collected because a nurse's task is to capture the data rather than directly use the information.

‘The nurses don't put much effort into collecting the data because they are not using the data themselves they are just capturing it to be used at the national level and analysed there. They are feeding the data in but getting nothing out.’ (*Expert 117, male*)

He said the problem with poorly collected data is ‘garbage in and garbage out’. This was echoed by a policy-maker who described the problems with data accuracy.

‘This is only useful when people on the ground can actually use it. There are no mechanisms to feed that data back or use the data. My feeling was they don't want anyone to use the data because of the concern about what the data would say.’ (*National policy-maker 99, female*)

She suggested that the more the data is used, the more evidence about the state of the country's health affairs will emerge.

In summary, there is a supportive policy environment for mHealth with the development of national mHealth programmes and the web-based DHIS coming into fruition.

Organisational systems: capacity for implementation and culture of information use

Is there a culture of and capacity for using information technology for management?

Leon *et al.* (2012:9) suggest one of the organisational challenges is how to ‘effectively align the use of mobile technology with the strategic goals and priority interventions of both national and provincial DOH’.

There is a culture of and capacity for using information technology for management (Leon *et al.*, 2015a). Experts believed that public health systems have the capacity both managerially and technically at the national level. Evidence for the management of eHealth at the provincial and district levels is weak. This is possibly because of eHealth immaturity. Programmes are not yet being filtered down. One province has its own agenda and is leading in terms of its organisation and use of digital communication. It is far more advanced because of budget allocations and prioritisations. Furthermore, in rural areas there are no functional ICT environments to support the use of computers by nurses. The management of digitally stored health information has been initiated through the DHIS. Evidence suggest different patient systems are being used among provinces despite the moratorium. To extend this to a full electronic patient record system, a shift in the culture of information use is needed. For many nurses, filling out multiple registries is an essential part of their job. There needs to be a shift from just inputting the

information, to understanding how the data is being used and to what effect. The NHI pilot clinics are an example of where frontline health-workers, such as nurses, are being specifically trained to use information systems.

National Health Insurance (NHI) as evidence for organisational systems

The NHI was described by one policy-maker as a ‘monster’ because of the sheer scale and work needed for its development.

‘We need to be able to implement the monster that is NHI, that is why we are doing this in NHI pilot priority districts.’ (*National policy-maker 99, female*)

She then qualified this by describing the NHI process as ‘the simplest thing ever, we have to track your transactions in the health system from birth to death while adding an insurance component’ (*National policy-maker 99, female*). However, the complexity of the NHI scheme must not be misjudged.

‘I don’t think we can underestimate the task at hand for the government.’ (*National policy-maker 105, male*)

Another argued that South Africa needs the NHI to improve the current health system.

‘We have a health system in South Africa but not one that we really desire.’ (*Provincial policy-maker 116, male*)

eHealth is an important part of the NHI’s development plans. All nine provinces have been involved in pilot projects, within 11 districts across the

country. A policy-maker described this preparation as creating the NHI backbone.

‘Already rolling-out the ICT infrastructure, the ICT hardware backbone in seven hundred facilities in the NHI priority districts.’

(National policy-maker 99, female)

Another policy-maker said that the government was moving fast and success hinges on the NHI pilot districts. The Agincourt study site was not within one of these pilot districts but a district health manager from one of the pilot districts in Mpumalanga was interviewed. He described the findings from the preparation work as ‘not in the public domain’ but suggested that the clinics needed improving in terms of computers for administration and software for patient information. One of the major objectives of the NHI is to ensure all facilities have connectivity so that clinicians are able to access the Internet.

‘We are putting lines or connections in all clinics and NDOH is providing or assisting us with the hardware.’ *(Provincial policy-maker 119, male)*

Given that ICT can exacerbate the existing socio-economic inequalities, connectivity can improve the current landscape and enable South Africa to move forward.

‘Connectivity is definitely a huge problem.’ *(Provincial policy-maker 118, female)*

The ICT skills of nurses were discussed, having seen the low level of computer-trained nurses in rural areas. The responses conflicted with the study site findings.

‘Rural nurses are trained and some have the skills already. As we move towards computerising our health information system, we will have to expand the training of frontline clinical people. Most of them in the primary care level are nurses, in 700 clinics, will be the first wave and be trained ensuring the patients are registered, biographical and medical records are done electronically. So clearly as part of that process nurses will have to be trained in ICT use.’ (*Provincial Policy-maker 119, male*)

This policy-maker also explained that nurses would order medicines on the computer system, replacing the faxing method, a similar system described by the pharmacist. There was much conviction in what the policy-makers thought about ICT skills training on paper, but little evidence in practice.

In summary, there is a culture of and capacity for wanting to use eHealth for management, as demonstrated with the NHI example. However, progress is slow and further commitment is required.

Technological systems: usability, interoperability, privacy and software

How usable, integrated and sustainable is the chosen technology?

Leon *et al.* (2012:11) argue when implementing any mHealth project, attention should be paid to the technological issues of end-user acceptability (feasibility studies) and interoperability. This includes the ‘technical and human resources systems to ensure security and privacy of patient information’. The acceptability and usability of technology by health-workers has to allow them to see a direct benefit to their work, such as time reduction.

The usability, integration and sustainability of technology should be user-driven. For example, findings from Chapter 6 illustrate that current levels of patient and health-worker technology use were self-initiated. If mHealth is adopted, both parties must perceive the technology as benefiting their work, business, society and health by enhancing the measures and processes they may already have in place. Technology should mediate their practice in a user-driven way.

Another example is the pilot project of Ward Based Outreach Teams (WBOT) in the North West province. CHWs moved from paper to mobile-based system to collect household indicators. There is a healthy development of software platforms designed in South Africa. This environment creates competition between developers to sell their mobile-based software packages to the government.

Ward Based Outreach Teams (WBOT) using CHWs

The NHI policy proposes that there should be a WBOT in each of South Africa's 4,277 wards (the smallest unit within a district). WBOTs are linked to a facility consisting of a team of five CHWs, who are assigned to 250 households per team. Their purpose is summarised by a senior policy-maker.

‘We can’t wait for the people to come to the clinics and utilise healthcare off their own back that is why there is a need for CHW to be sent to households to find those at risk or already in ill-health and not in the system yet... We are using it for the mechanism for early detection, health promotion, community empowerment and advocacy.’ (*National policy-maker 100, male*)

Formalising mHealth monitoring and evaluation systems for primary healthcare outreach and delivering community-based services can offer greater accuracy and ‘enhance supervision’ (Neupane *et al.*, 2014:1), yet still evidence is limited. An evaluation of the CHWs using mobile-based software to record various health indicators, such as pregnancy, at the household-level was conducted. The study authors found that the phone system saved time, making referrals more efficient. Challenges observed included ‘mobilising necessary funding, reorienting training systems towards supporting mHealth and creating the capacity for on-going technical support’ (Neupane *et al.*, 2014:7). These are likely to be similar for other mHealth projects, where the issues are unlikely to be the technology, but instead the support mechanism,

financial constraints and training which allow for phone-based systems to be successful.

In summary, the usability, integration and sustainability of the technology should be discussed, as with the case of the WBOTs, if the technical systems of any mHealth project are to survive past the pilot.

Financial systems: sustainable funding and cost-effectiveness

Is adequate financial provision being made for the medium- to long-term use of eHealth and mHealth?

Leon *et al.* (2012:8) argue that small-scale local feasibility rather than effectiveness projects do not always allow us to know whether the benefits shown will be realised at scale in ‘a routine public sector environment’.

Adequate financial provision is being made for the medium- to long-term use of mHealth in certain priority health streams. The cost-effectiveness of the mHealth Strategy is at the forefront of the government’s agenda, but this is beyond the bounds of this thesis. However, the financial implications and longevity of MomConnect are explored.

MomConnect mHealth pregnancy programme

MomConnect cuts across all four health system dimensions and for this reason it is the mHealth programme analysed in the most detail. MomConnect

is a national, at-scale, interoperable programme that seeks to subscribe, identify and register all pregnant women in the country for a stage-based SMS service that provides antenatal advice. The South African mHealth community has deemed it a ‘trail-blazing initiative... using technology to reduce maternal and child mortality’ (*National policy-maker 105, male*).

Before MomConnect was launched, pregnant women in the Vutivi study were asked hypothetically whether they would value receiving health-related information to their mobile phones. Findings suggest that many pregnant women would be very receptive to receiving mobile messages from the clinic. This was partly because there are limited opportunities for educational advice other than from the clinics. Those who could not read said that they enjoyed looking at the images on clinic posters, suggesting that there is scope for picture-based messages to be sent to function phones, perhaps with sounds relating to the visual. These could also be shared with other mothers via their phones using Bluetooth at no cost. One expert said that literacy rates among pregnant women are average and why messaging is a viable means of getting information across.

‘Most pregnancies occur between 18–35 years and most of these people have gone to school. As poor as our school system is, I think this cohort can read.’ (*Expert 98, female*)

In addition, the pioneer of MomConnect admitted that not everyone would benefit.

‘We thought that even when the mother is illiterate there is still someone who can read the message. There are obviously going to be some people who are not going to benefit from this technology. We hope this is a small percentage and they will not be further disadvantaged by not being able to get it.’ (*National policy-maker 98, male*)

The development of MomConnect

MomConnect was developed by a multi-expert team as a collaborative partnership between the NDOH, non-profit and private-sector representatives, many of whom participated in the Vutivi study. The Task Team had a wider remit of assisting government with developing their mHealth Strategy and interoperability foundations. They produced a document on the foreseeable limitations of the programme. These included the possibility of duplicate registrations, limited incentives for CHWs to promote registration and the unsustainable financial burden on donors and government. They also discussed the benefits of the programme, in that it ‘ensures health messaging is consistent and harmonized at the national level, while being adapted and extended for local environments and aligns the different service providers to current NDOH objectives’ (NDOH, 2014b:3). Since the programme is still in its infancy, only one academic paper (at the time of writing this thesis) on MomConnect has been published. Waldman

and Stevens (2015:4) suggest that the programme reflects ‘the priorities of the Minister and his desire that health messaging reach at least a million women. Messages were developed with the aim of achieving a balance between technical, medical jargon and colloquial language’.

One of the Task Team representatives warned that MomConnect was only a tool and would not solve all challenges.

‘Is not a panacea to all the problems of the health system. It is about one tool. Most mothers or their households have access to a cell phone.’ (*National policy-maker 98, male*)

The reason that the first mHealth programme was designed for maternal, newborn and child health was because the government had to start with one of the nation’s health priorities. A key advisor explained that the purpose of the programme was to empower women.

‘Even though we have a quadruple burden of disease, one of the key things is high maternal mortality in South Africa. We know what the causes are, we can intervene on the supply side and felt we needed to do more on the demand side. This is far more a demand-side intervention to empower pregnant women.’ (*National policy-maker 105, male*)

An expert said that during the development of MomConnect ‘there was very little DOH employee involvement’ (*Expert 166, male*) because the Task

Team were directing it. The deputy director did invite NDOH employees to the meetings to contribute but they did not attend.

‘I don’t know if they don’t contribute because they don’t want to or if they don’t have time or skills or if government doesn’t want them.’

(Expert 166, male)

The government did not have to use external organisations such as, NGOs as they could have attracted dynamic department members.

‘They actually have those people working for them but the bureaucracy is as such it doesn’t allow or encourage people to move outside of the constraints of their very defined and over-burdened positions.’ *(Expert 166, male)*

One of the Task Team members said that the planning of MomConnect was a long process.

‘We have been planning this thing for 18-months already, it’s not like we got up one morning and decided to do it. We are building on what we have piloted in various places over the last few years. All we are doing really is expanding it and taking it to scale.’ *(National policy-maker 105, male)*

The same policy-maker was re-interviewed to give an update on how the programme had fared since its launch 12-months previous. He explained the on-going additions to the programme, which had reached nearly half a million women, ‘slightly under the target but not bad, not as good as I hoped for. We

hoped for 600000.’ On the one-year anniversary of MomConnect, Minister Motsoaledi spoke passionately about the programme’s importance. The MomConnect helpdesk received more compliments than complaints. Impact will be measured and defined by key national maternal and child health indicators, specific to antenatal attendance, immunisations, mother and infant HIV testing and measures of behaviour change through pre- and post-knowledge assessments. Process measures regarding the performance of the registry and support services will also be collected (NDOH, 2014c:3). The government’s aim is to extend messaging to nurses to help boost their capacity called ‘NurseConnect’ (Seebregts *et al.*, 2016:125).

Messages can only be received in five of the 13 South African languages: English, Afrikaans, isiZulu, isiXhosa and Sesotho. Women in the study site cannot currently choose Xitsonga. It can be argued that the government should have translated the messages into all South African languages from the onset to ensure that all pregnant women can be included. There is an opt-out feature should the mother wish to stop receiving the messages for any reason. This is particularly important if the pregnancy has had a traumatic outcome, such as a stillbirth. It can be argued that, in this instance, psychosocial support should be offered through additional messaging or face-to-face counselling at the clinic where the mother is receiving antenatal care.

Opinions of MomConnect from both policy-makers and experts

The policy-makers and experts gave their opinions about the future of MomConnect, which reflected their belief in taking mHealth programmes to scale.

‘This is a government directed, owned and initiated project and the minister will be watching and waiting to see if this is going to work. They [*NDOH*] have taken a template, which has been tried and tested.’

(National policy-maker 98, male)

An employee of a parastatal organisation said that some women might already be receiving pregnancy messages from other sources. There may be issues with the cross-contamination of possible conflicting information.

‘We need to make sure something like MomConnect is not sending conflicting messages to mothers who may also receive similar messages from a different provider which is not government.’

(Provincial policy-maker 119, male)

Another critic of the programme reacted by questioning how the pregnancy registry would actually improve early antenatal visits.

‘My first question was “What’s the point of registering all pregnant women?” There is no objective to this. You have a nice little database, so? It seems an exercise of futility on some level. Setting up an electronic registry that is dependent on a women doing a pregnancy

test at a facility, is not going to in anyway promote earlier antenatal visits you know.’ (*Expert 120, female*)

The NGO employee also argued that a poor evaluation of its pilot project concluded that only 70 per cent of pregnant women, who signed up at the facility, had mobile phones. She explained that the remaining 30 per cent of women, who are probably those who are most in need and with the fewest resources, are not going to be supported.

‘National MomConnect messaging doesn’t address that at all. Again it is focused on the individuals without considering the limitations of the technology in terms of the issues of equity and public health.’ (*Expert 120, female*)

She was very concerned about pregnant adolescents under the age of 18 receiving a MomConnect message.

‘What happens if you get a 16 year old girl who gets a message on her cell phone saying “Hi you are at 28 weeks and you should go back for your next antenatal care check” and her father reads the message’ (*Expert 120, female*).

The implication of a family member finding out before the adolescent has told them about the pregnancy is controversial and has to be considered. Another perspective was the programme is only of value if improvements from the current paper-based registration are seen.

‘You have to see if something works in comparison to what is currently in place. Compare traditional paper registration versus mobile. The case itself is presenting the value of mHealth to the payer.’ *Expert, 121, female*)

Financial implications of MomConnect

The cost of sending text-messages is an important point related to the Nkateko mHealth component. This type of intervention can never successfully go to scale because the government will not fund the cost of text-messages or phone call appointment reminders. This is unless the telecommunications companies are supportive in reducing the costs significantly.

‘Cost is definitely is a very big one, when it comes to anything to do with SMS, which is really the way that patients are going to be impacted the patients that we want to reach.’ *(National policy-maker 98, male)*

The NDOH has enough funding for MomConnect to demonstrate whether it works.

‘I am confident that the cost will come down significantly over time as South Africa gets more advanced and there is more pressure on operators.’ *(National policy-maker 98, male)*

However, more women are going to be using smartphones in the future. This means the NDOH are going to have to develop more sophisticated messaging

services, which will increase service costs significantly. The government would keep the basic phone messaging systems because ‘mHealth should not increase inequity’ (National policy-maker 98, male).

Implementing MomConnect at the provincial level

One concern at the provincial level was that MomConnect would be yet another register for nurses to fill out.

‘The nurses are already complaining because of the work they have to do to data capture.’ (*Provincial policy-maker 118, female*)

It was too early to appreciate whether MomConnect was an effective tool, as it had not been rolled-out at the time of research.

‘Its efficiency is not known in the province. It’s hoped to be an effective tool to register pregnant women. The knowledge acquired will hopefully lead to good outcomes.’ (*Provincial policy-maker 101, male*)

Future evaluation of the MomConnect programme

The impact goal and indicators are related to neonatal and child mortality. Critics of MomConnect argued that reducing maternal mortality is the gold standard and this will prove the effectiveness of the SMS intervention. One expert said that providing the service was a good start but it will not be a quick fix for reducing maternal mortality.

‘We can provide them with information but is that necessarily going to translate into reduction in maternal mortality in the deep rural settlements and communities that are the most beset with all of these associated health system issues.’ (*Expert 122, male*)

Generally, the policy-makers were in support of the programme’s future.

‘Maybe over the next ten years the dots will be connected more and more. I am hoping that MomConnect will be one of the big dots.’
(*National policy-maker 105, male*)

Another expert had a very results-based approach to the programme’s longevity.

‘The minister is going to be watching and waiting and see if this is going to work. I suppose the proof of the pudding, is in the eating! If it is going to be a successful intervention, it must become part of government’s strategy otherwise it is not valued.’ (*National policy-maker 98, male*)

A Task Team member said that the programme will be a waste if the results are not successful.

‘I am a results-based person, so although the process has been interesting and fun, if it does not achieve anything then it has been a bit of a waste.’ (*National policy-maker 105, male*)

MomConnect does not include HIV-related messaging. One policy-maker believed that this ‘requires more of a systems effort to deal with chronic

conditions'. He said that the department 'shied away from asking if women are HIV positive' (*National policy-maker 98, male*). A perfect system could not be developed all at once.

'I think that once it is going we will be able to add on things such as a more dedicated HIV messaging service.' (*National policy-maker 98, male*)

An expert responsible for contributing heavily to the mHealth Strategy explained both sides of the NDOH.

'Government is very reactionary and very ambitious. I have been involved in pilot project in one district to then be a national programme. Without really learning from what happened in that district because the Minister wanted it to happen that way and the Minister did not want to fall behind.' (*Expert 122, male*)

In summary, there was a clear disconnection between the optimists and the realists within government about how much MomConnect may achieve. It is clear that the Task Team was fundamental in the inception of MomConnect. This process should be an example to the development of future mHealth initiatives. The overhaul of the health system, using digital communication has to be grounded in basic training and learning about what eHealth and mHealth can achieve at the district and provincial levels. This includes how they can be supported over time. Otherwise expectations will not be met and

resources will be allocated for the wrong reasons. The government needs to be decisive about future eHealth and mHealth budgets, if programmes are to be sustainable and without donor dependency.

‘It has been a slow plodding process, very traditional very donor dependent. We don’t have a mechanism to continue this outside of the USAID money.’ (*Expert 166, male*)

MomConnect is only donor-funded for a period of three years. The government wants to see clear indicator outcomes of the programme’s effectiveness. This suggests that the NDOH was prepared to scale a programme in the knowledge that donor funding is not sustainable. The ‘freemium model’, asserted by the GSMA, will work if the MomConnect service has free-of-charge and premium financial charge components. The premium aspect could target more affluent urban-dwelling pregnant women, but usually this cohort does not use public health facilities. From the study site findings, it seems unlikely that rural women would pay for government SMS services.

Given that MomConnect is still to be evaluated, the rapid launch of another app, called B-Wise for adolescents, indicates that the government is getting ahead of itself. However, they are feeling pressurised to fill the information gap for another priority group.

B-Wise youth app

One year after the launch of MomConnect, a mobile application called B-Wise was launched for the country's youth. It allows 10 and 24 year olds to engage in live chats with experts about sexual health. The population group of adolescents was chosen because the Youth Health Strategy is being revised. One policy-maker said that he wanted to harness the current trend of younger people being the predominate users of apps.

‘So I thought that one way of popularising both the Strategy and asking the questions that adolescents have rapidly, would be through an app. They use apps more than probably anyone else.’ (*National policy-maker 105, male*)

The policy-maker explained that there could be an overlap between MomConnect and B-Wise since many of the pregnant women are adolescents.

In summary financial provision for the future use of eHealth and mHealth is being debated but no real long-term solutions have been decided upon. MomConnect is an example of the government's ambitious action ‘taking the bull by the horns’.

This section has described the four health system dimensions necessary for successful eHealth and mHealth solutions to go to scale, and has given

evidence of these using examples. However, there are a number of barriers and enablers for adoption.

7.5 Policy debate by policy-makers and experts around the barriers and enablers of the future of eHealth and mHealth in South Africa

The opportunities (enablers) and challenges (barriers) to the future of eHealth and mHealth uptake in rural South Africa are now discussed by drawing on analysis from the previous results chapters.

Challenges to the successful implementation of eHealth and mHealth according to policy-makers and experts include: the country's disease burden, staff capacity, the sustainability of pilots, the mindsets of the end-users, resource barriers such as phone signal and policy, financial, practical and managerial barriers (Table 32). In the Government Budget Speech (2015), the Minister discussed the definition of a weak health system as, 'weak health facilities, infrastructure and equipment, low number of health professionals, poor supply chain processes and financial management' (Motsoaledi, 2015:2). Many of the experts echoed and described these weaknesses as challenges in the adoption of digital communication systems. Leon *et al.* (2012:10) suggest that the major weaknesses in the functioning of the public primary healthcare system 'could jeopardize the successful implementation

and value of mHealth programmes’. This section attends to these weaknesses as potential barriers to implementation, which link and follow on from the challenges identified by health-workers explored in Chapters 5 and 6.

Table 32. The barriers to eHealth and mHealth implementation in South Africa with evidence from the Vutivi study

Barriers to eHealth and mHealth implementation	Explanation from the Vutivi study	Evidence from policy-makers and experts
Disease burden	Issues within the health system could be blamed on many of the chronic diseases	‘I think there are an overwhelming number of sick people. Blame it on HIV, blame it on TB, blame it on whatever you want to blame it on.’ <i>(Expert 36, female)</i>
Staff capacity	Nurses having to constantly fight the system because of the patient capacity compared with staff numbers. A lack of supervision of junior doctors by senior clinicians.	‘I think all the nursing staff are a little bit tired because of these thousands of cases and it is hard to fight a system for ever.’ <i>(Expert 36, female)</i>
Sustainability of pilot projects	A proliferation of unsustainable pilot projects in the country that had not moved to scale. The cautious nature of the government reflects that they want to be sure about their investments. Since all provinces are at different levels of eHealth maturity, it would be wise for purchasing and financing decisions to be made at the national level	‘You can prove the concept in the pilot but you can’t prove the cost effectiveness and other thing until you try and scale it up.’ <i>(National policy-maker 98, male)</i>

	so they can determine exactly what each provinces needs and requirements are and where they are starting out from.	
mHealth projects in silos	Everything works in silos and there needs to be greater collaboration.	‘I am sure you are very well aware how many silos there are in the DOH both vertically and horizontally and diagonally, any which way you can think of.’ (<i>Expert 120, female</i>)
Social – Health-workers mindset	The mindset of users of new technology is a well-cited barrier to change.	‘South Africa is still under-resourced. It is a ‘mindset’ that people don’t want to learn how to use new technology or maintain it.’ (<i>Expert 124, male</i>)
Structural and environmental	Overcoming connectivity issues through the development of rural communities. Agreements with mobile phone providers and telecommunication companies like Telkom, South Africa’s largest telecommunications company to ‘come to the party and not mess us around’ (<i>National policy-maker 100, male</i>). Collaboration with other departments such as The Department of Communications who are also responsible for infrastructural rollout in South Africa necessary to aid the broader development of South African citizens. Broadband roll-out has to be a collaborative effort.	‘I think there is no reason why these things can’t be overcome in the course of time but there needs to be a lot more emphasis on rural development and looking at rural cases.’ (<i>Expert 108, male</i>) ‘Network failure and no electricity in some rural areas, poor phone lines and road networks and overall poverty’ supported this. (<i>Provincial policy-maker 101, male</i>) ‘In many places there is still no connectivity and without it you halt the rest of the eHealth Strategy because it depends connectivity.’ (<i>Expert 108, male</i>) ‘Wi-Fi, free to the community to enable communication, especially the Internet. The service will provide a good link between the health facilities and the community.’ (<i>Provincial policy-maker 101, male</i>)

	<p>Wi-Fi should be accessible to everyone in the community acknowledging this will improve patient-health-worker communication.</p>	
Government structure	<p>Provincial autonomy has been raised as a barrier to eHealth adoption. Provinces have so-called ‘concurrent powers’ in the constitution. The necessity of interoperability but also the difficulty in embracing it because provinces are very much free agents with different health priorities. Currently no provincial systems can ‘talk’ to one another. The speed at which the government works is a major issue.</p> <p>Poor capacity of provinces and districts to use health information for management, which could limit the potential value of new technology.</p>	<p>‘Constitutionally, we have a serious hindrance that provinces have autonomous power in so far as the health provision and implementation is concerned.’ (<i>National policy-maker 102, male</i>)</p> <p>‘Major problem is political interference.’ (<i>Provincial policy-maker 126, male</i>)</p> <p>‘eHealth is essential in rural areas, but you know the issues, the government is so slow.’ (<i>Expert 123, male</i>)</p> <p>‘Many senior managers in government they do not understand ICT. They only talk about ICT when they have viruses on their computers! This becomes a major bottleneck to development.’ (<i>Provincial policy-maker 126, male</i>)</p> <p>‘[The DOH] has different ideas, different budgets and different objectives...’ (<i>Expert 120, female</i>)</p> <p>‘It’s a very good tool [<i>eHealth Strategy</i>], you know, at least for rural places but if people don’t want to stand up and kick start it, it’s going to fail. We don’t say technology replace must people but it will assist in helping them with some of things.’ (<i>Expert 123, male</i>)</p>
Economic	<p>A recurring theme was the concern over the cost of eHealth and mHealth related to sustainability. It</p>	<p>‘The number one barrier that prevents mass-uptake is around cost of usage. Getting free services is tricky and as we know two out of three women attending the clinic don’t have</p>

	may not work if the service is not free because the majority of women do not always have airtime on their phones and so many will be excluded.	airtime on their phones. Then if you ask them to use a mobile health service they must pay for you straight away have a problem.' (<i>Expert 108, male</i>) 'MomConnect has been working very much around the 'reversed-bill approach'. Negating cost that people can then use for free is when it is likely to be used.' (<i>Expert 108, male</i>)
Practical	A SMS-based intervention can be translated into all South African languages.	'I mean there are challenges, like people share phones or they can not afford them or the number falls away they get a new number. When you want to phone someone you do not necessarily get them on the end of the number they have given you, it is like the neighbour or someone.' (<i>Expert 36, female</i>)
Management	Hospital management must be overhauled for implementation to occur.	'We have the correct people in the correct position. Like even some of our CEOs are not properly placed, they do not have the knowledge and the expertise we are also looking in terms of our HR management.' (<i>Provincial policy-maker 118, female</i>)

Summary of the enablers to eHealth and mHealth

Even though the barriers presented in Table 32 are in need of further research into how they can be overcome, there was also evidence of enablers for success of digital communication development. If present, the four enablers are the health system dimensions of government stewardship and organisational, technical and financial systems.

A provincial policy-maker summarised the enablers that may assist with eHealth and mHealth adoption.

‘Good telephone network reaching even the most remote areas, the availability of handset for phones and SMS services and Internet services, bulk SMS marketing at affordable cost, stable power supply from Eskom [*South African electricity public utility*] and use of local language to communicate.’ (*Provincial policy-maker 101, male*)

Phone ownership among the majority of the public is high. The numbers of patients who owned a mobile phone or had access to a phone in this study, confirmed this.

‘In this country, in spite of the fact we have high levels of literacy – poverty and unemployment... if I can put it like this... some of your poorest people have cell phones... some of the guys [*citizens*] have more than one phone.’ (*National policy-maker 100, male*)

Summary of enablers to successful mHealth implementation

- *Moving from mHealth as a buzzword to becoming normalised within the community and health system.*
- *Society becoming less resistant to change and the uptake of current technologies for different health related purposes.*
- *Government preparedness to take risks.*
- *Incremental steps to move to scale.*

- *An understanding of the end-user (patient and health-worker).*

Summary of the policy debate

In response to realist question of ‘what works ...’, the CMOc for the enablers of and barriers to the use of digital communication for the delivery of primary healthcare in rural South Africa is as follows:

Theme 10: Enablers and barriers of eHealth and mHealth implementation (landscape)

C¹⁰ – foundational eHealth and mHealth strategies in place but slow implementation of policy and now revisions. Greater investments are needed. Evidence of government commitment. Often uncoordinated and fragmented mHealth pilots. Financial constraints as a major barrier. Long budget cycle with a reliance on external funding to support health priorities. Mobile network providers’ costs remain high, as demand has not escalated yet.

M¹⁰ – resources as enabling mechanisms such as risks/less reactionary to change/incremental steps/understanding of the end-users.

- *Government Stewardship* – through DHIS. Key eHealth and mHealth champion.
- *Organisational systems* – shifts in the culture of information use, necessary to create the NHI backbone. Interoperable system. Management and accountability of digital communication programmes (theory of change management).
- *Technological systems* – through WBOTs. Health-worker skills training.
- *Financial systems* – prove cost-effectiveness through MomConnect.

O¹⁰ – Health information systems within NHI, mHealth programmes adhere to government guidelines. mHealth becomes normalised into healthcare delivery. Patients and health-workers’ digital communication increases as the four health system dimensions improve chances of successful scale-up.

The context in which this would not work is when the barriers outweigh the enablers and the government stops supporting, providing and evaluating the

resources for eHealth and mHealth programmes to develop. This CMOc describes the barriers as the context, and opportunities to the uptake of digital solutions, given the resources are present. This theory was used in the development of the framework to follow.

7.6 Developing a health systems healthcare delivery framework for decision-making around eHealth and mHealth

The overall aim of this chapter was to develop a framework inclusive of patient, health-worker and health system perspectives. The proposed theoretical framework (Figure 26) of integrated findings from Research Questions 1-4 is informed by theory and evidence. In line with health systems research thinking, this thesis and the subsequent framework has been influenced by Oni's *et al.* (2014:36) systems thinking of redesigning healthcare delivery models.

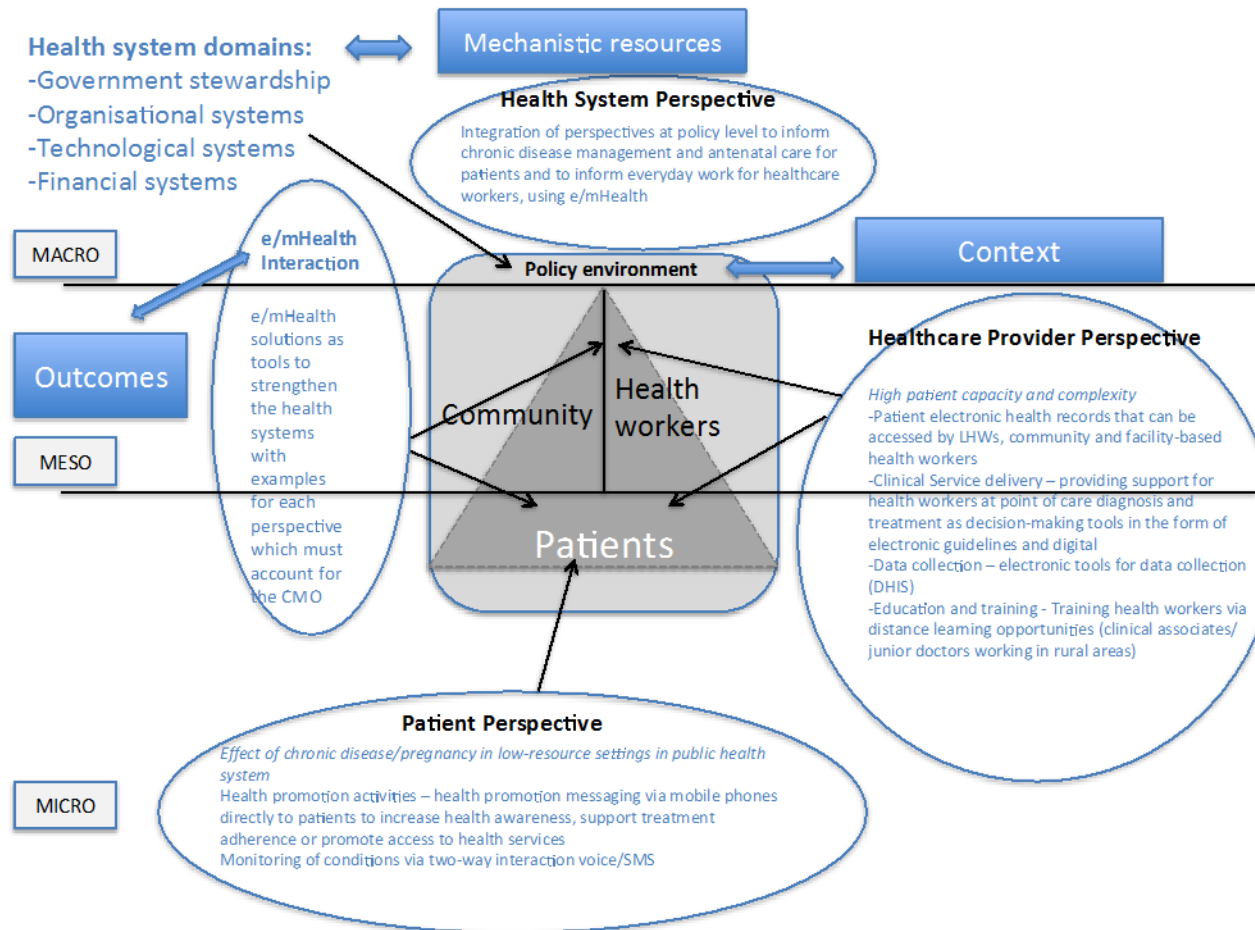


Figure 26. Vutivi study framework of a healthcare delivery model* to illustrate the interaction between eHealth and mHealth policies, health-workers and patients to aid the strengthening of the South African health system

**The layout of this diagram has been adapted from Oni et al. (2014:36), a modification of the Innovative Care for Chronic Conditions (ICCC) framework by the WHO (2002:45) and the South African Integrated Chronic Disease Management (ICDM) plan. Vutivi study adaptations are indicated in the blue text and are related to eHealth and mHealth.*

Explanation of the healthcare delivery model

This framework (Figure 26) has been designed using the CMOc from theme 10 and the results from previous chapters. The model depicts the micro-, meso- and macro-levels of digital communication system development and the perspectives of the patient, healthcare providers and the health system. Specific digital communication examples are presented under each perspective. The triangle depicts the interplay between the perspectives and the influence of the health system domains and policy environment.

The policy environment (as the context) is top-down at the macro-level (the tip of the grey triangle), which affects the health-workers and community at the meso-level and patients below it at the very micro-level. The macro-level represents the overall eHealth and mHealth ecosystem, directed by the four health system enabling domains of government stewardship, organisational, technological and financial systems (as the mechanistic resources). The upward oval represents the digital communication interactions (as the final outcome) that can strengthen the health system (macro), healthcare provider (meso) and patient (micro) perspectives. For example, at the health system perspective level, policies to inform chronic disease management and

antenatal care – such as, the MomConnect programme or the NDOH symptom checker website, are in accordance with the four political domains. At the healthcare provider level, the street-level bureaucrats, for example the nurses, guide these policies. The providers implement policy change such as improved electronic data collection or clinical service delivery via digital reminders. At the patient level, there is an increased use in digital communication to improve daily monitoring, education or awareness. This will, over time, improve access to information, continuity of care and ultimately maximise health gain.

For all three of the perspectives to be synced, the four domains as resource mechanisms must be present. Overall, this will strengthen the health system if there is an understanding of the key barriers and enablers to successfully using mobile or non-mobile digital communication within this context. This framework can be used by programme implementers to decide what is required to scale-up eHealth and mHealth programmes. This model may be useful for policy and practice decision-making in other LMICs, if the policy environments and health systems are similar. Future research requires more qualitative research into the perspectives and experiences of health-workers' usage of mHealth technologies to deliver primary healthcare services as their use becomes normalised in routine practice. This theoretical framework and

the previous cog diagram will be used in the discussion of the final framework in Chapter 8, to demonstrate how to move from policy to practice.

7.7 Conclusion of Chapter 7

This chapter has met the objective of exploring with policy-makers and experts the current digital landscape in South Africa and its potential for improving healthcare. In conclusion, government stewardship, organisational, technological and financial dimensions can act as enablers and barriers and must all be considered when designing digital communication for the delivery of primary healthcare. The presentation of Figures 23 and 26 are used to consolidate and further synthesise the results in the final discussion chapter.

7.8 Strengths and limitations of Chapter 7

The strengths and limitations presented here are relevant to the results in this chapter.

Strengths of Chapter 7

This study included interviews with many senior policy-makers and relevant experts, who are not always easy to access at this level of research. Chapter 7 is a result of patience and a determined recruitment strategy. The effort

involved to contact stakeholders and make interview arrangements must not be understated.

Limitations of Chapter 7

It is likely that not all eHealth and mHealth projects have been covered because of the scope of this research and what is presented is only what participants discussed. This research was conducted during 2014 and, while efforts have been made to make sure all up-to-date information has been included, many projects have been further developed since this information was acquired. However, the analysis of the results is still relevant.

It was very difficult to find any information about the work roles of policy-makers and experts prior to the interviews. Therefore, interview schedules were left open. This required me to ‘think on my feet’ and act decisively during each interview.

Interviews with local mHealth project employees were not conducted because there were no known active projects in the study site at the time of the fieldwork. One high school was taking part in an eEducation programme, but this was not health-related and was for adolescents (ethics permission was not requested to interview people under 18 years old or to research in schools). There was a reliance on projects being described by organisations happening elsewhere, especially in rural areas. A demonstration of the phone interface

for the pilot of MomConnect by a research institute affiliated with a South African university gave hands-on experience of how SMS platforms are created and piloted.

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Chapter 8 will present an overall discussion by cautiously interpreting the findings and suggesting implications for policy and future research. The conclusion will reflect on the contribution of the Vutivi study to the field of health systems research.

Chapter 8



Photo 23. Two Shangaan women walking home from the clinic in the study site

Chapter 8: Discussion of the Vutivi study

8.1 Overview of Chapter 8

Chapters 5, 6 and 7 presented the main results from the Vutivi study. This final chapter aims to summarise the key findings (the macro-themes and refined middle-range theories) by synthesising and discussing the results and realist hypotheses in light of the literature and theory. The strengths and limitations of this thesis are described, followed by a discussion around the implications for policy and practice and future research before culminating in the thesis conclusion.

8.2 Introduction to the thesis discussion

The overarching goal of this thesis was to better understand the potential for digital communication to improve healthcare delivery in rural South Africa, using a realist question of ‘what works, for whom, in what circumstances, in what respect and why?’ The aim of this chapter is to consider what might be possible using digital communication solutions in order to help strengthen service delivery. This chapter will address how digital technological change may become integrated into normal provision within the community and health system.

This chapter will link the results together. In doing so, five overarching themes have developed as the core thesis results. High-level recommendations for government and other relevant stakeholders are discussed throughout. These are likely to be important for the future use of digital health communication. There was little available high-level eHealth and mHealth theory in the literature therefore the theoretical framework from Chapter 1 guided this study. The overall synthesis is mapped into the model to follow.

8.3 Synthesis of final research findings with recommendations

The first synthesis of results is of the realist theories developed from the realist literature review into the interpretation of the core empirical findings. Pawson and Tilley (2004:15) suggest ‘the goal is to produce a tested theory about ‘what works...’. This emerging theory can help lead to better focused and more effective programmes. Based on the review and primary research, preliminary CMO configurations as the hypotheses or ‘candidate theories’ (Wong *et al.*, 2013:19) for each macro-theme were identified. Realist guidelines denote that from these CMOc, desired outcome patterns emerge by consolidating the theories (CMO¹⁻¹⁰). These re-occurring patterns within the data are known as ‘demi-regularities’ (Pawson, 2006:23). Patterns from all ten C¹⁻¹⁰ + M¹⁻¹⁰ = O¹⁻¹⁰ configurations suggest the following final realist theory:

Given that a foundational eHealth and mHealth ecosystem exists, this can help support a health system that has many challenges (C). If government stewardship, organisational, technological and financial systems support digital health solutions that include support line, observation, reinforcement/feedback, reminders, educations/advice, decision-support, motivation, health promotion and information (M) that can improve communication between patient and health-workers or health-workers and health-workers. This in turn, increases access to healthcare, continuity of care and possibly maximise health gain (O) because work practices are made more efficient, health service delivery is enhanced and patient outcomes can be improved.

Future research could test this refined theory with other high-level theories such as the ‘Technology Acceptance Model’ (Davis *et al.*, 1989:983) derived from the Theory of Reasoned Action. In particular, when a programme has been designed to understand how ‘internal beliefs and attitudes [*reasoning*] are, in turn, influenced by various external factors [*context*]’ (Davis *et al.*, 1989:983). This was achieved in Kenya by Smillie *et al.* (2014:333) using mobile health for early retention of HIV care. The qualitative study considered the perceived ease and usefulness of new technology, whether the person believed they should perform the behaviour or not, the individual’s attitude towards the behaviour and their intention to engage in a behaviour.

The proposed refined realist theory can be supported by high-level access, normalisation and capability theory.

Final Vutivi model of synthesised results

The development of this refined, more coherent theory has been tested from a wide range of sources and is visually demonstrated below in Figure 27 with five overarching themes.

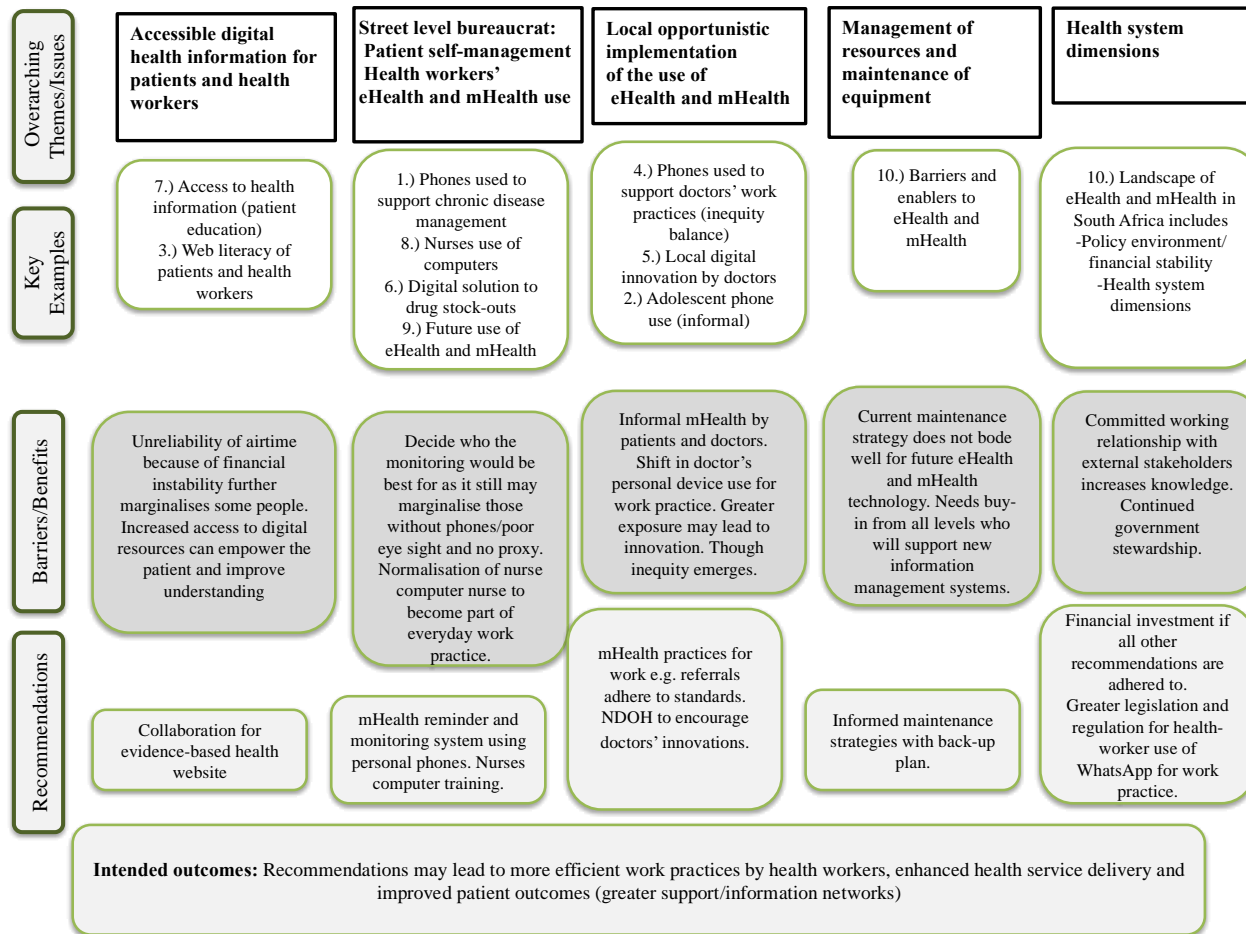


Figure 27. Model of overall results inclusive of the overarching themes/issues, key discussion examples, barriers/benefits and recommendations

This model depicts the original contributions of this research. The key overarching themes that emerged from each research question are now discussed with recommendations interwoven.

Lack of accessible digital health information for patients and health-workers

The lack of accessible digital health information for patients and health-workers suggest the need for a coherent source of digital information. Current web-literacy levels are either non-existent or poor among patients and nurses. For the minority who are intermittent Internet-users, their use is immature and ad hoc depending on opportunity to access resources, digital skills and financial ability to pay for services. The implication for this is retrieval of wrong and potentially invalid information, from online sources. Schools and clinics need to play a role in Internet safety where skills and the development of ‘web-based resources are accurate, realistic and up-to-date’ (Hampshire *et al.*, 2015:26). An evidence-based health website promoted by the NDOH is recommended. This could be created as part of the health system strengthening to contribute to the equitable access to essential technologies that are ‘scientifically sound and cost-effective’ (Gilson *et al.*, 2007:12). More community Wi-Fi hotspots would allow a higher percentage of users

onto the website. Increased accessibility will further marginalise those who do not have the means to access the Internet or the ability to pay for online services if using 3G.

Many patients felt their primary source of health knowledge was from their clinic. This is an intriguing policy point because patients' network of health learning needs can be potentially widened through digital means. Digital communication could improve the channels through which a patient receives health education by text-message, podcasts or animations via Bluetooth, targeted to their condition. This can be extended to non-patients as key prevention messages. Public health campaigns could be driven through messaging services for greater reach. This may also extend to information and promote 'equitable access' (Van Rensburg, 2014:1).

The correlation between increased access to the Internet and the ability to search for health information to improve health status is unknown, requiring investigation. If access to information is extended through digital means, the NDOH can define appropriate online resources. Only these sources can then be publicised by health-workers for their and patients use. Government approved mHealth programmes that adhere to the normative standards can be advertised. Patients and health-workers would benefit from an evidence-based platform accessible via a mobile or desktop website. This has potential to empower both parties. During the health talks, nurses could provide

education classes to teach patients about Internet searching and advocate a website similar to NHS Choices '*Your Health, Your Choices*'. An online resource made accessible to those who have the Capability, Opportunity and Motivation to use the health resources, can then be shared within the community and to those not able to use the Internet. This could also extend to CHWs, who could use it as a learning resource and decision-support tool whilst in the community. Scullard *et al.* (2010:580) recommend that health-workers could 'encourage' patients to use websites for health purposes. It is recommended that health resources are available in different languages as patients could only search online in English.

A symptom-checker website can become an important resource for the community, whether the person is a patient or not. There may be consequences of opening-up a new online arena for people to seek health-information. Health-workers would need to acknowledge this may increase the number of people who are concerned about their health so visiting a health facility, impacting on the health system. Nurses need to be prepared that patients are starting to use the Internet as a resource for health dialogues. As patient become more informed they can no longer be treated as ignorant health users. Primary healthcare may not have the capacity for this, given the high-patient to staff ratios in rural areas. This speaks to the 'patient-centred' approach because a more informed patient can change the dynamics from

being a passive recipient to an active consumer of health information during the patient-health-worker interaction (McMullan, 2006:24).

The website may be linked to the National Laboratory Service and any diagnostic apps that health-workers use. The website would have to be culturally relevant to patients, with additional advice about medical pluralism, combining traditional medicine and western medicine (Pantelic *et al.*, 2015). Mehl and Labrique (2014:1286) suggest channels of communications such as voice, text-message and mobile web need to be expanded ‘to inform pregnant women from different social strata about appropriate nutrition and remind them of antenatal care practices and available services’. Then the goals of universal health coverage can be more quickly realised. If a text-based messaging system is in use, this also needs to be supported up by a website and a phone hotline so a range of possibilities are available for people to find the necessary health information. It would be beneficial if the NDOH ‘developed accessible ways of navigating across and between different digital health platforms and sites, so that people can find and access the kinds of information they desire and need’ (Waldman & Stevens, 2015:8).

Patients expressed interest in seeking virtual health-workers for advice. This was apparent when they felt stigmatized, shy, required help out of clinic hours or needed to reassert their understanding of treatment or symptoms. Patients reported using WhatsApp groups and online forums to discuss their condition,

concerns and learning with peers. By establishing more formal online adherence clubs, this could act as an additional support mechanism, for those more isolated and with less proxy assistance. Luque-Fernandez *et al.* (2013) and Wilkinson (2013) found that adherence clubs, as a retention strategy for clinically stable patients receiving ART in South Africa, is an effective model. Whether this could be extended to formal digital adherence clubs needs further research. For example, being digitally monitored by a CHW.

The lack of accessible digital health information for patients and health-workers also relates to the actual implementation of digital technology for work and health practices. This is now discussed under the lens of the street-level bureaucrat.

Street-level bureaucrats' implementation of policy and programmes

The ability of patients to self-manage using digital reminders or mobile monitoring systems is likely to be beneficial in improving clinic attendance and the monitoring of chronic diseases. Although recommended, both systems are costly to the provider. A home-monitoring system could be outsourced to a private company but distributed and managed by the NDOH. Any digital system would have to complement rather than replace a patient's current management strategies. Patients have to be given an incentive to self-monitor and be supported by a system for nurses to respond in a timely manner. Digital systems would not only enhance communication between the

patient and health-worker but is likely to improve social connectedness and motivation. Results from the realist review confirmed that given the mechanistic resources, such as feedback, exist; it is likely that digital communication can improve patient monitoring. It is unknown how long-term this may be effective for.

Besides enhancing the digital skills of patients, many nurses were eager to engage and learn themselves. Some were resistant to change due to their own confessed laziness. They recognise that work processes such as digital registers, data collection for the DHIS and drug re-ordering would become more efficient. This should not take the nurses longer than current paper-based practices if they understood the usefulness of working electronically. Connectivity must be stable and reliable. Nurses' use of computers for work tasks may be limited by apathy and unwillingness to learn new technology-based skills. This is known as 'digital drudgery' (Selwyn, 2013:1). This may extend to their managers who would need to provide adequate ICT support and supervision. Normalisation of computer use will take time to become part of everyday routine and how clinics are eventually run. Digital technology use can amplify and augment its own intensification due to work tasks becoming more digitised. It is recommended that nurses are taught ICT skills when they are still training as student nurses. Junior nurses are going to have greater exposure to technologies as access to digital devices becomes more

common. The idea of the street-level bureaucrat is useful in bringing together some of these themes and examples.

‘Policy implementation in the end comes down to the people who actually implement it’ (Lipsky, 2010:9). Walker and Gilson (2004) argue that the practice of policy change can be viewed through the lens of the street-level bureaucrat. Gaede (2016:2) argues,

‘in the tension between the top-down policy-making and the bottom-up pressure, street-level bureaucracy acts as an important terrain for improving the implementation of services and therefore advocacy and health system improvement’.

Public sector health-workers can act as liaisons between policy-makers and citizens. They are the implementers of policy, interacting and communicating with the general public. Nurses, as the ‘frontline providers’ (Lehmann & Gilson, 2013:359), are considered as street-level bureaucrats in this study. They are the people at the grass-roots level delivering the digital communication interventions from government to patients. The nurses as the ‘bureaucrats’ then change the policy in the process of implementation by making different policy decisions at the coalface of their work. Their role as street-level bureaucrats is only likely to increase with the future rollout of the NHI. Not only are the nurses going to be using technology to improve the delivery of patient care but also in their everyday ‘labour’. Digital systems

may reduce the autonomy nurses have over their work if the systems become more standardised. The informal and formal use of digital communication by health-workers will increase their ‘digital labour’ (Selwyn, 2014:55) to an extent that is still unknown.

Patients are then affected by the street-level bureaucrat’s policy decisions, such as the way they are cared for and how they are advised to manage their condition. The use of mobile digital communication in self-management would require the patient to act out the intervention. This is supported by health-workers and stipulated by policy. Policy-makers at the provincial level suggested that there is a need to link the patient to the health facility and community services by communicating through a mHealth platform. This would allow for the monitoring of compliance and adherence to treatment, linking to the review findings in Chapter 3. The review proposed additional monitoring by patients using their mobile phones at home as this can alleviate monthly vital sign monitoring by nurses. The government could use a system such as Piette’s *et al.* (2014) design of an independent mHealth automated phone and tele-management support tool tested in Bolivia. Cost implications need to be considered due to high numbers of chronic patients accessing care through public facilities. By improving the management of chronic disease in primary care using digital means, services can be strengthened (Beaglehole *et al.*, 2008).

The Vutivi study found a general acceptability of digital reminders delivered via phone calls to the patient's own phone. This concurred with Leon's *et al.* (2015b) study where text-messages were sent to urban-dwelling patients as clinic reminders, including treatment advice. Reminder systems are useful to patients in both urban and rural settings. Forgetfulness has been repeatedly cited as a common or significant reason for failing to attend clinic appointments and non-adherence to ART in LMICs (Liew *et al.*, 2009). In the Vutivi study, Nkateko patients said they either forgot their return date, or did not have transport money to attend. Madhvani *et al.* (2015) suppose that patients who failed to attend appointments differed in characteristics such as age, education level, employment, marital status and phone ownership. Further, large-scale research into the type of patients who forget their appointments needs to be better understood.

Leon *et al.* (2015b:8) have established that text-messages increased some patients' 'awareness' about the need to take more responsibility for managing their own health. Reminders sent two-days before their appointment date allowed the hypertensive patients time to plan their journey to the clinic. Although, the Nkateko patients received the call only 24-hours in advance and this also proved sufficient. This shorter timeframe seemed an adequate duration for the patient to be reminded. The Nkateko (Thorogood *et al.*, 2014) and SMS-text Adherence Support (StAR) interventions (Leon *et al.*, 2015b;

Bobrow *et al.*, 2014) are the only known hypertension trials to use a mHealth component. This may be why there are similarities between study findings and between the rural (Nkateko) and urban (StAR) settings.

Madhvani's, *et al.* (2015) study on HIV messaging found that patients who were significantly less likely to benefit from digital clinic appointment reminders were patients over 45-years, women and those with only primary or no schooling. They found that patients with lower monthly incomes were less likely to use mobile phones for medication reminders. Life stressors such as poverty mediate their ability to routinely adhere to treatment, as the Vutivi findings suggest. The majority of patients were not comfortable with accessing and reading a text-message and reported technical difficulties receiving the message. Therefore LHWs switched to voice-calling the patients. The LHWs also preferred to make a call rather than send a text-message because it gave instant confirmation that the person had received it, whereas it is unknown whether a text-message has been read.

When aspects of healthcare are delivered using digital technology, it can become integrated into normal provision within the community and health system. To be an optimal candidate of normalisation, complex interventions (the use of computers for work practices) need to fit with an actual set of roles within the health system. The technology must be capable of integration within the existing patterns of service delivery (May, 2006). For

normalisation of computer use to occur amongst nurses, constructs of skill-set workability need to exist. Firstly, there has to be a distribution of the policy for specific actors (nurses) and the identification of skills need to use computers (technology) for defined tasks (entry of data into DHIS/ordering of drugs). This is followed by the capacity of agents to organise complex interventions within a healthcare setting. Over time this becomes instilled into every-day work practices. However, as one of the experts suggest it is a 'mindset' that people are resistant to new technology and its maintenance, so this would have to be reconciled. If student nurses are trained in computer skills as part of their nursing degree, they will begin their careers with an already normalised skill-set. The endorsement of digital up-skilling will be beneficial for work practices, especially for junior nurses who are unfamiliar with paper-based methods of working.

There is capacity for using information technology for management by increasing access to electronic information to ensure quality improvements in the health service. It is well-known that effective governance, leadership and management need good and accessible information to make health management decisions (Chaudhry *et al.*, 2006). However there is not yet a culture in doing so. There is an urgent need to change the filing system into an electronic system to improve referrals and discharge notes. Krist *et al.* (2014) suggest that electronic patient records must have meaningful uses for

primary healthcare-workers. Nurses would have to understand the usefulness of an electronic system over paper files that go beyond quick retrieval.

From a patient's perspective the idea of normalisation is related to that of their capability to use technology. By understanding and assessing the conditions in which complex interventions can be introduced and normalised in healthcare are important to all levels of agents; the patients, health-workers, managers and policy-makers. This idea of context relates to the realist philosophy around the importance of local settings and the mechanisms by which knowledge and practice about complex interventions are distributed. This may result in the outcome of normalisation over time. The normalisation model also compliments Michie's *et al.* (2013) psychological model of behavioural change, as it aims to mediate practice by changing behaviour.

Using the lens of the street-level bureaucrat to understand how policy can be implemented, this relates to the current differentiated experiences of patients' and health-workers' technology use. This can lead to local opportunistic implementation on the ground for reasons to be discussed.

Local opportunistic implementation of the use of eHealth and mHealth

There has been a distinct shift in the nature of digital technology use particularly by doctors who have very differentiated experiences. Some are using their phones to assist in everyday practices, making their work more efficient, such as the retrieval of blood tests, remote diagnoses and referrals

via messaging platforms. These informal practices are mostly self-initiated and often prerogative to a minority of health professionals. They are usually a privileged group with personal access to smartphones. This can segregate and disadvantage other doctors who are not able to use or access the same resources. An imbalance then occurs between doctors who are able to improve the ways they can work and potentially override some of the challenges faced in their health facility environment. Those with greater exposure to technology and skills, often locally innovate by advancing their self-initiated practice into a more developed system. This was evident with Vula and Thumela. Localised adoption, adaption and creation have to fit well with current health system practices in order to successfully mediate change. For example, a digital referral system can be accessible to all doctors, if they have access to smartphones and are willing to use them for work (the context). Greater dialogue between the doctors who are often the innovators, the NDOH and other stakeholders, will allow for some of the challenges to be resolved. Discussion of how digital communication innovation can be scaled-up in rural contexts and where they were designed, can be on the government agenda. Policy-makers, funders and regulators need to 'actively encourage innovation and entrepreneurship' to drive change (Kumar *et al.*, 2016:5).

Likewise, adolescents' phone use is often informal and navigated by their desire to access health information and resources via their current social networks. However, digital skills are needed to traverse and cross-reference

useful verbal, physical or digital resources for chronic disease and pregnancy. The B-Wise app can enhance and encourage this learning. Online forums and social media can lead to gossip that can be habitually detrimental to a person's wellbeing.

There is a lack of research into the informal ways that rural South African patients, in particular 18-24-years olds, use their mobile phones for health-related purposes. Hampshire *et al.* (2015:22) found that young people in South Africa are using phones 'creatively and strategically' in an attempt to secure effective healthcare. The Vutivi study is in agreement that adolescents with chronic disease and adolescent pregnant women are resourcefully using their phones to enhance their healthcare utilisation via social media and the Internet. This does not hold true for everyone, as only a minority are navigating websites to find health advice, contribute to online discussion forums and chatting with other people in similar health states.

The idea of 'social capital' in relation to technology use involves not just the ownership or access to the technology itself (the mobile phone) but the actual ability and capability (personal networks, skills, resources) needed to optimise use. Digital capital is multi-faceted and unstable over time. A lack of digital capital is perpetuated by a lack of other forms of capital that impact on healthcare. 'Young people need to be facilitated to build appropriate digital capital to use mobile phones to best therapeutic effect' (Hampshire *et al.*,

2015:26). Some participants lacked the appropriate resources, social networks and skills (digital capital) combined with on-going shortcomings in public healthcare delivery (queues, drug stock-outs) that are out of their control. Goudge *et al.* (2009) suggest that often livelihoods are exhausted from previous illness or death in the family, toppled by low-income and limited social networks. Digital social media may therefore increase a person's social networks by expanding their face-to-face networks with online peers and communities. Whyte (2014) argue that patients need both the 'technical know-how' and 'technical know-who'. The right contacts need to be extensive, well-resourced and well-positioned, coupled with skills to access relevant information and help. Many of the patients made use of these contacts for health-related matters, such as messaging a relative for a pregnancy-related query. There was huge variation of phone use for health-related activities within the HDSS because the community had different resources, social networks and needs for healthcare utilisation. Hampshire *et al.* (2015:19) said 'differential access and opportunity were more likely explanations' for differences amongst their study participant's responses. This is likely to be similar for Vutivi participants.

The Vutivi findings are also in agreement with the findings of Hampshire *et al.* (2015) in that young people are not waiting passively for mHealth to come to them. They are already 'doing' mHealth informally by 'using mobile phones creatively and strategically to try to secure healthcare, laying claim to

a digitally medicated form of therapeutic citizen' (Hampshire *et al.*, 2015:1). Hampshire *et al.* (2015:22) exclaim this fits well with patient empowerment, choice and responsibility. Patients are participating in a geographically dispersed and largely unregulated digital healthcare arena. For example, patients seek online health advice from online forums, social media discussions or are searching 'Dr Google' (Lee *et al.*, 2014:262). This was encouraged rather than discouraged by Vutivi doctors as they felt at least it was opening up new opportunities for patients to access health information for themselves. Thus becoming a more-informed patient rather than relying on vague sources such as health posters. Hampshire *et al.* (2015:23) argue that the unregulated nature of the digital world presents difficulty and risks since patients can struggle to navigate a potential 'minefield of misinformation because of the volume of unsolicited information'. This extends to health-workers such as nurses, who are using search engines to find health information with little understanding of the validity of the source. Hampshire *et al.* (2015:14) discovered that South African youth became anxious when they found conflicting or confusing advice online and were 'unsure how to assess its accuracy'. Patients in the Vutivi study did not discuss confusion over the information retrieved but would confirm their findings with a nurse. These results portray an urgent need for an evidence-based online resource.

As expected and as found in Hampshire's *et al.* (2015) study, the reach of informal mHealth is usually limited when it comes to the poorest rural communities. This is where the need to overcome healthcare barriers is the greatest. This includes the cost of phone use. 'Digital technologies tend to map onto existing, often deeply-rooted social inequalities that become re-configured but not removed' (Hampshire *et al.*, 2015:24). This thesis argues that digital technologies, even in rural areas, do in fact facilitate opportunities, if access to phones and airtime is feasible, combined with the appropriate social networks. Efforts may be compromised by limited access to technology, lack of digital capital, and poor health service provision, usually experienced by those in impoverished rural settlements.

The National Development Plan (NDOH, 2012a:23) acknowledges that the use of digital communications is changing society in ways that are not yet fully understood. The government is aware that young people have embraced social media and this represents a potentially powerful means of fostering social inclusion. This is supported by the younger Vutivi participants who were active users of social media. Although some adolescents found that social media was a distraction from their schoolwork and was an arena where people gossiped. Warschauer (2004:44) describe this pattern as different degrees of digital social inclusion. What needs to be better understood is who has greater privilege and the reasons for this, as this may not necessarily

correlate with household SES. Phone ownership is not a determinant of high-SES, yet the ability to continually buy airtime may be.

Inequalities develop amongst health-workers who have the ability to improve and enhance work practices realised through digital access and engagement with technology. There are implications for non-secure messaging of text and photographs of patient data that have to be resolved. The other consequence of exposure to ownership of smartphones is greater opportunity to locally innovate by using mobile resources to develop health work practices and overcome challenges. Local innovation will only be successful if there is adequate staff capacity to cope with referrals and give treatment. The government can support localised innovation by encouraging its use so that it has wider reach for all health-workers. If the NDOH ensures that all mHealth projects are regulated and passed through the eHealth steering committee, then they will comply with the normative standards. This will also improve and reduce the number of fragmented and overlapping mHealth programmes.

Local digital innovation will be effective if properly managed and maintained once implemented and scaled.

Current issues of management of resources and failure to maintain equipment

Issues of mismanagement that have a counteractive affect on maintenance strategies of resources and equipment are likely to be similar for digital solutions. If these are not resolved dis-benefits are probable for the longevity of digital communication systems. Better maintenance plans need to be adopted and adhered to. The ICT investment will only be effective and sustainable if there is greater buy-in by managers and health-workers who want to improve current systems, otherwise valuable resources will be wasted. Investments into digital health can only be advocated if the health system is strengthened through better maintenance strategies and change management theory. If the provincial and district DOH are held ‘accountable’ (WHO, 2007:13) for these, they may use resources more effectively. If not, health system actors can be held publically accountable. An understanding of the contexts and multi-layered practices of power, may allow managers to adopt more appropriate management strategies (Lehmann & Gilson, 2013:358).

Current maintenance strategies are often inadequate and will impact on the success of digital technology uptake. This is often a result of mismanagement at the district level. Transient positions create issues of poor management and leadership within the facilities. This can affect procurement of new clinical-based equipment such as computers. The results of a poorly-managed health

facility can be an indicator of where digital communication tools may struggle to be sustainable. Challenges faced by health-workers will affect the adoption of digital communication systems such as poor network signal. Whether mHealth can change managerial problems, poor clinical leadership and hospital management, is yet to be reconciled. eHealth and mHealth may support the challenges, creating a better delivery of care and thus a better performing health facility. Likewise an eHealth champion are described by Wade and Elliott (2012:490) as ‘essential contributors to the success of telehealth services... by providing continuing motivational, educational and organisational support’.

Above the facility level management are the policy actors who exercise some form of power. An understanding of the complexity of local realities, interests and contexts and the multi-layered practices of power, may allow managers to adopt more appropriate management strategies (Lehmann & Gilson, 2013:358). Greenhalgh and Russell (2010:2) imply that eHealth initiatives often occur in a complex fast-moving socio-political arena where ‘the complexity of eHealth as a management challenge has been vastly underestimated’. If management is currently a barrier to maintenance and drug stock-outs, managers at both the district and provincial levels need to be clearly supervised about the adoption of new ICT to ensure longevity. Poor management of equipment and human resources within the hospital was a

reoccurring theme in this study, as in the literature (Kotzee & Couper, 2006; Cullinan, 2006; Dieleman *et al.*, 2009). There may be serious consequences on the uptake and effectiveness of digital solutions unless there is government awareness around the strengthening of rural hospital management. Without buy-in from hospital managers and health-workers, consistent monitoring, evaluation and maintenance of digital and electronic resources, and the sustainability of any intervention, programme or policy, will be curtailed.

The usability, sustainability and integration of digital technologies are going to be the government's greatest challenge. Challenges in health facilities are compounded by equipment failure, lack of accountability for when equipment breaks and an ingrained mindset that the problem is someone else's responsibility. Sub-standard maintenance strategies are a major barrier to the uptake of any novel digital solution in public health system within already constrained environments. If a definite maintenance strategy, grounded in the eHealth and mHealth policies, is defined from the onset and forms part of management training, there is a likelihood that digital communication systems will function. All stakeholders can feel accountable to its success.

The factors that enable and challenge the integration and adoption of eHealth and mHealth as a solution to health system challenges in rural South Africa are often compounded by financial constraints. Financial stability is a barrier. Adequate financial provision made for the long-term use of digital

communication by the NDOH has not been made. External donors are, in the short-term, funding the most prominent national mHealth programme. Current budgets for the development of eHealth and mHealth do not align with the government's enthusiasm delivered in both strategies. This will only be reconciled once the evaluation of the first phase of MomConnect is complete as a policy-maker said 'the proof in the pudding, is in the eating'. In Waldman and Steven's (2015:28) study, they suggest that the NDOH 'had to steal money from other pots to launch MomConnect'. One of their respondents referred to this as 'ADHD within the NDOH – they jump from one thing to another'. The Vutivi study also found that money had to be sought from various sources. The current donor-funded model is not sustainable. This is unless mobile operators forfeit profit gain for the sake of public good, as the government will not be in a financial position to continue funding the stage-based messaging, whilst registered women will exponentially grow. The GSMA's (2014:29) report found that willingness to pay for services such as maternal health messages does not equate to the ability to pay.

Issues of poor-management that can affect the ability to suitably maintain resources will also be affected by the financial stability of eHealth and mHealth programmes. Other dimensions such as stewardship was also addressed in this thesis.

Health system dimensions as enablers and barriers to implementation

Many of the eHealth and mHealth programmes are currently externally funded and the government is aware that for these to be sustainable, a larger budget from treasury is required. Donors are funding the majority of mHealth services planned or being deployed with little or no long-term plan. Leon and Schneider (2012:8) regard this as ‘vulnerable’. It is important to understand who is investing in digital communication technology, who is playing a role and in what capacity: as the payer, producer, provider or consumer.

A consequence of the supportive policy environment is the backing of external stakeholders, such as the eHealth committee and Task Team. Nurturing these relationships from the onset is of great benefit to the future of digital knowledge-sharing. It is not only the NDOH’s responsibility. Other government departments need to work together to ensure infrastructure continues to improve, as there is a health agenda in most policies.

Further investment into laying down the digital foundations in preparation for the NHI will demonstrate to the presidency the commitment and investment the NDOH has made to the initial development of eHealth and mHealth. In addition, greater legalisation and regulation through official bodies is vital to ensure patient confidentiality.

The four health system domains of stewardship, organisational, technical and financial systems for making decisions about acquiring and scaling-up mHealth were updated. Leon *et al.* (2012:8) argue that it ‘remains unclear the extent to which, new technology can achieve a fit with the dimensions of the current public sector health system’. However, now the digital landscape indicates a direction towards making progress within each dimension. In particular, some of the technological challenges include the complexity of ensuring interoperability and integration of information systems and securing privacy of information. If national policy is informed by evidence-based decision-making, this can lead to sustainable programmes and effectiveness within a national digital health system as indicated in Figure 28.

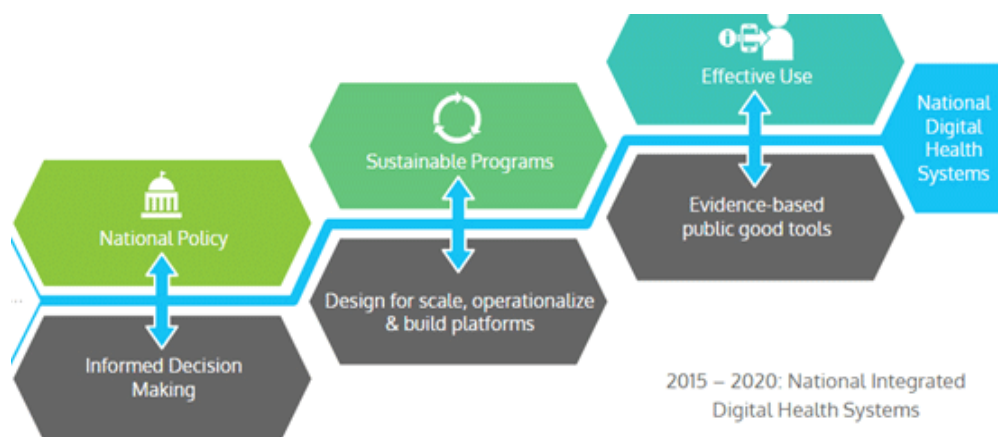


Figure 28. National Integrated Digital Health Systems: 2015-2020
(*HealthEnabled, 2015:1*)

If the relevant executive policies that effect upon eHealth and mHealth are examined carefully and objectively, it can then be determined whether or not they may have a different impact in rural areas. Many of the government

pilots have been in both rural and urban settings. This was to ensure they provide effective interventions that fully account for factors that define the rural service delivery context. There is a requirement for policy adjustments to be made to reflect rural needs. Policies can be ‘rural-proofed’ (RHAP, 2015:142). For example, the strategies need to ensure that public services are accessible on a fair basis to rural communities. If not, inequities of the uptake of digital services between urban and rural areas will continue.

8.4 Summary of the research findings presented in Chapter 8

The final model (Figure 27) proposes that under each overarching theme, there are key examples from the Vutivi study. These have both barriers and benefits to the end-users and the health system. Recommendations have been suggested. For example, if a collaborative evidence-based health website existed this would improve the validity of the information accessed by patients and health-workers. Digital reminder systems can assist with reducing non-attendance at chronic disease appointments and are beneficial to patients with hypertension. Informal mHealth use leads to innovation to either improve health or work practices. However inequities can emerge. mHealth use by patients and health-workers are often currently informal and self-initiated. Health-workers act as the street-level bureaucrats, as the policy implementers for more formalised or self-initiated digital programmes. Stakeholders, including the NDOH can build on these existing informal

digital practices by encouraging mobile communication companies to lower airtime costs. All of the aforementioned recommendations will only be a useful investment with demonstrated improvements in workflow and health outcomes, if maintenance strategies are improved under committed managers as agents of change. This, along with increased financial resources and greater regulation and standards, need to be better understood if digital systems are to be sustainable.

8.5 Overall strengths and limitations of the Vutivi study

Strengths of the Vutivi study

There are a number of recognised strengths. Firstly, a major strength of this thesis is how the empirical results relate back to the realist review results, by extending the realist approach into the discussion. This was achieved by developing the middle-range hypotheses into a more consolidated and refined overall theory, in response to the central realist question of ‘what works...’. Related to this are the novel frameworks and discussions as a key contribution of this research. Four frameworks are presented in this thesis. An integrated theoretical framework encompassing all relevant theories is illustrated in Chapter 1. The development of a theoretical framework for mHealth interventions and programmes for monitoring of chronic disease is proposed in the realist review in Chapter 3. A healthcare delivery model demonstrating the interactions between the layers of the health system is in Chapter 7.

Finally, an overall framework of thesis findings is presented in Chapter 8. The purpose of the last three these frameworks is to consolidate the results and theory and present a practical model that can be used by researchers, programme designers and policy-makers in the implementation of digital communication systems. The frameworks proposed are related and influenced by each other as shown in Figure 29. The red arrows illustrate the links between the frameworks and diagrams, discussed at depth in their respective chapters. The four main frameworks are numbered in the order in which they appear in this thesis.

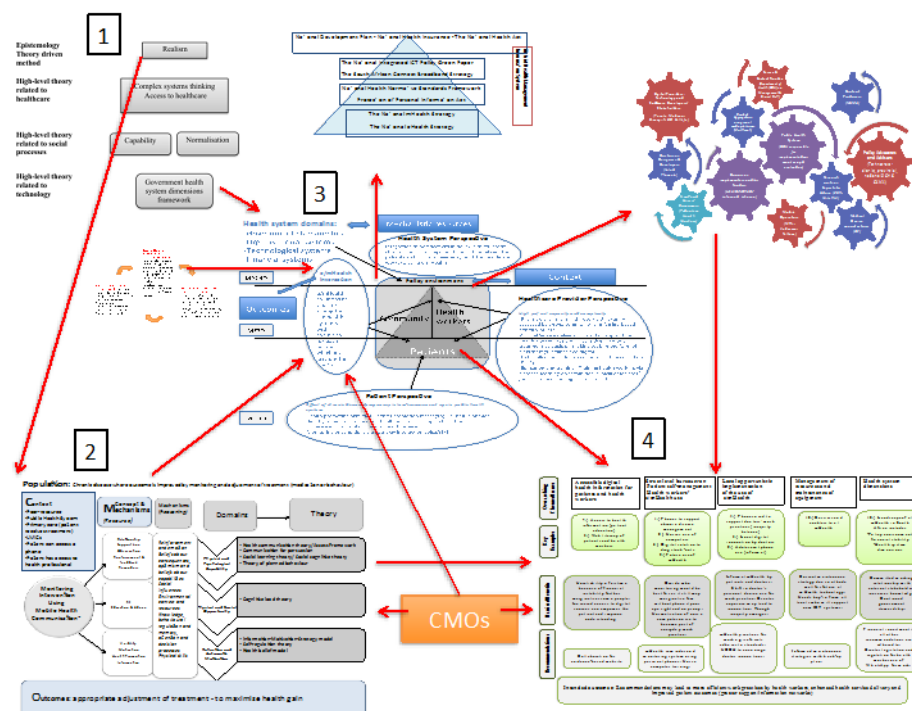


Figure 29. Thesis frameworks and diagrams with links indicated

Another strength was the familiarisation with the study site over a three-month period. This allowed for in-depth formative observations and informal conversations to transpire, before a further nine months of data collection occurred.

There is too much uncoordinated and ‘fragmented research’ (Orgill *et al.*, 2012:158). This thesis has therefore brought together a coherent critical analysis to understand the potential role of digital solutions within the South African context.

Methodological strengths of this study include a large sample of qualitative interviews ensuring diversity in each participant group. It was necessary to interview to saturation and diversity to allow for a broad range of participants. Most chronic participants ranged between 18-88 years and were male and female.

Multiple qualitative methods allowed for the triangulation of findings. Observations supported interview data, for example. A qualitative approach was important in allowing for participant-led identification of need and resource. A high level of corroboration between participants on a number of themes resulted.

The secondary data descriptive analysis benefited from access to the HDSS census database. This allowed for the more variables of linked patients to be compared to the study site population.

Another strength was that the study was embedded within an existing demographic surveillance site. This study benefited from the relationship between the Agincourt HDSS and the community, harnessed over twenty years. The community's perception of this research was important and relevant to their health and lifestyle concerns.

The lack of problems with recruitment and therefore ability to access a wide-range of participants was helped in part because of the long-standing relationship that exists between the community who live there and the Wits research staff. The benefit of the LINC team in supporting study preparation was crucial to the success of the study because of the established links with the HDSS, the health facilities and in particular the nursing staff. The clinics and community showed interest and engagement with the study. The study topic caused intrigue amongst patients who were only too willing to participate, enabling ease of recruitment. The nurses expressed their desire to want to learn computer skills and how they have been asking for training for years, to no avail. They made it clear that as researchers, we must return with information from the study, which could be used to inform their understanding of digital communication technologies and what this means for

primary care. Research dissemination to nurses in the form of a PowerPoint presentation, followed by a question and answer session, took place in June, 2016. All seven clinics sent a nurse representative and they were all very excited by the Vutivi findings. This positive engagement can be of interest to the government who can further foster the health-workers' interest in digital communication.

The ability to have a rudimentary conversation in Shangaan and follow verbal exchanges, assisted with building rapport with clinic staff and patients. This extended to facility security staff, cleaners and counsellors. During the initial greetings and introductions, it was explained to participants that I was not a clinician but a student researcher who grew up in rural South Africa. This immediately helped with participant trust and engagement as I was accepted as in 'insider'.

A procedure was in place to check for accuracy of translations and quality of data. This included an independent translator to transcribe ten per cent of all patient interviews conducted in Xitsonga. This ensured original meaning was translated accurately from the fieldworker's interpretation of the patient's initial response.

The research was important for extending the research agenda in the Agincourt study site. It is possible that the findings may significantly advance

efforts to understand new technologies that may be used in the rural clinics to better serve facility users.

Findings are transferable to urban areas or to other population groups, because digital communication is becoming a phenomenon in many places. Patterns of mobile phone use may not differ hugely with other groups who may experience similar mobile signal, price of airtime, availability of phones and exposure to social media and the Internet.

The NDOH adopted Leon's *et al.* (2012) Health Systems Framework to highlight what is required for the uptake of eHealth and mHealth into mainstream health service delivery. The extension and update to this framework from the Vutivi study findings allowed for the research questions to be addressed.

This thesis attended to the policy continuum, from policy formulation to implementation. Research Question 4 discussed the formulation of the mHealth Strategy through to the programme implementation.

Finally, this thesis made progress in understanding the causal pathways of mechanisms of change for mHealth monitoring using realist methodology. This study highlighted the need to underpin future phone-based adherence interventions along with behaviour change theories. This will take cognisance

of the complex mix of psychosocial and health service influences on ‘adherence behaviours’ (Leon *et al.*, 2015b:1).

Limitations of the Vutivi study

There are several recognised limitations of the study design often attributed to the time and resource constraints of a doctorate.

Many of the interviews were opportunistic. A larger number of participants were included to reach data saturation and diversity. Adequate time was given to the fieldwork process to allow for a large sample.

The patient sample was restricted to Black Africans. They were predominately Xitsonga-speaking community members engaged with the health system, who lived within or just outside of the study site, accessing care at local health facilities.

Patients who were labour migrants and lived away from the study site were not represented in the sample unless they were at ‘home’ temporarily at the time of research. The patient sample only included non-migrating individuals permanently residing in the study site (although some women did return from their migrant jobs to give birth). Migrants may have had different technological experiences due to different exposure. In urban areas there is greater access to services, better phone signal, more advanced users of

technology and possibly more opportunity to use technology within the work place.

The study did not compare different tribes, languages or settlement types with other locations in South Africa such as urban areas where residents largely reside in townships. It would have been beneficial for the same study to be conducted in an urban setting to allow for comparison.

The patients who participated in the study were already within the health system. Therefore members of the public who were not currently accessing or seeking healthcare were not included in the sample. Community members were not asked directly if they were patients. Undiagnosed patients not known to the clinics would have been impossible to identify, unless clinical measurements were taken during recruitment as the Nkateko trial team did.

Patient recruitment through the HDSS database may have allowed for a more random and purposively diverse sample of people. However this would have meant interviewing people in their own homes where they may have been more reluctant to talk about their health because of lack of privacy. It would have been logistically and geographically difficult to physically go to each person's house and invite them to participate. Also, not all patients were necessarily 'patients' at the time of the last census collection and were diagnosed post-census. The database does not necessarily hold accurate information on each community member's chronic disease status, since the

census data is collected from only one member of the household who may not know accurate details on each family member or neighbour.

The choice of method was determined by the research questions and objectives. These did not warrant the use of a quantitative survey. The use of 'positivistic experimental methods' was not needed to complement the descriptive methods (Valle *et al.*, 1989:150). In future research, survey questions could generate greater numbers of peoples' general phone behaviours. Greater financial resources to employ more fieldworkers and time would be needed.

Policy-makers and experts are not identifiable by organisation or department in this thesis. This decision was based on ethics regulations that all participants would remain anonymous. Some of these participants made it explicit when they expressed something that must not be repeated or published. This made it incredibly difficult to code transcripts when some responses to questions could not be used for analysis since they were given in good faith. For this reason, a form of member-checking was done whereby participants were emailed 'uncertain' parts of their transcripts to check if they consented to a particular section of the interview being analysed. Only two experts refused for the data to be published since they risked being identifiable. Research findings were only circulated among respondents for review and feedback if a query or concern was raised. Member-checking was not possible for all other participants because of the large samples. It would

be particularly difficult to track patients again because their home addresses were unknown.

The constraints of second-language translation by the fieldworker have been recognised. The qualitative fieldworker had transcribed many of other research project interviews and is highly proficient in English. In addition, no quotes transcribed were incomprehensible therefore stylistics and grammar inaccuracies were not edited.

Since two of the clinics were outside of the HDSS, it was not possible to match all patients to the Agincourt database, as they did not live in study site villages. This is why only a small number of Vutivi participants were included in the quantitative sample in Chapter 5.

Several patients assumed I was a doctor because of my presence at the health facility. Even as a researcher, some participants may have changed what they were willing to say because of the perceived power dynamics between us. This was considered during analysis.

These limitations did not affect the collection of data to answer the research questions.

The synthesis of the overarching themes has conveyed several implications for public health practice and policy and future research recommendations.

8.6 Implications for public health practice and policy

This section presents the potential implications for policy implementation from the research findings. Waldman and Stevens (2015:22) found that even where there is good policy, implementation can be challenging as often ‘policy is not sufficiently correlated with need’. Findings from the Vutivi study can go some way in informing the implementation of policy for particular participant groups. Tentative policy suggestions are presented since Cluver (2006) warns that extreme caution should be given to the extrapolation of policy implications from research findings.

This research has a number of broad implications for public health practice and policy. These findings are intended to act as a guide for research, policy formulation or intervention design. eHealth and mHealth in South Africa can strengthen the health system if it becomes normalised within the everyday experiences of end-users. With the current policy in place, findings suggest that the likelihood of successful implementation over time, can occur if the barriers are considered. If teachers and nurses are educated in Internet safety then this could be passed on to learners and patients. Greater pregnancy support for first-time mothers, who are temporarily out of school to give birth, would be beneficial.

If an evidence-based health website existed and was accessible to both health-workers and patients for symptom-checking and clinical guidance this may improve the channels through which information is accessed. It could also include a platform to seek mHealth programmes. This highlights the importance of both practical utility and relational aspects of mobile reminder interventions in a clinical setting. It may have the potential to improve adherence behaviour if the patient regularly attends the clinic and takes responsibility for their condition. Enhancing the communication channels by which patients and health-workers can communicate could strengthen service delivery. It would be useful for policy-makers to consider how research could distinguish between different chronic diseases with differing requirements.

In line with the ‘Strengthening Health System Effectiveness’ (NDOH, 2015a:13) table, the government’s mHealth examples are extended. Table 33 presents a list of eHealth and mHealth opportunities related to service delivery interventions. It would be useful for the NDOH to consider the opportunities presented with specific Vutivi examples from the overarching themes.

Table 33. Summary of suggested eHealth and mHealth opportunity for service delivery interventions and overall health system strengthening to guide scale-up with Vutivi study examples

Service delivery interventions defined by the NDOH	Opportunity for eHealth and mHealth (Vutivi)
Strengthen health information system and referral system	Use the web-based DHIS for decision-making. mHealth platform used by

	health-workers to strengthen the referral system (such as adopting Thumela and Vula Mobile) if the system has capacity for increased referrals.
Part of re-engineering of primary healthcare approach to reduce morbidity and mortality	Extend remote diagnosis via WhatsApp between specialists to a formal secure telemedicine system for rural patient care.
Improve the functioning of clinic services and reduce queuing times in clinics	Appointment scheduling system that sends reminders to patients via text-message and extends to adherence messaging on a similar scale to MomConnect but for chronic patients.
Improve functioning of clinic services and reporting of stock-outs	mHealth system to notify low-drug stock levels at facility level.
Health promotion and disease prevention at the household and community levels delivered via mobile platforms	Mobile communication infrastructure used for educational information channels for the public.
Monitoring of equipment and maintenance strategy in place	Continuous checks that eHealth systems are working. Greater supervision from the provisional and district level.
Provision of training for health-workers	Internet safety and design of an evidence-based NDOH health website for patients and health-workers to access information.
Improve patient care and satisfaction	System for patients to formally monitor their chronic disease using their phones, in a more structured manner, with two-way interaction. This can then be monitored by the health-workers and patient medication adjusted if necessary.
DOH ability to manage contracts and maintenance	Improve management of contracts with private companies who sell the DOH the technology. For example broadband providers.

The research suggestions account for the complexity of incorporating digital communication solutions into a low-resource health system. These are not only directed towards the NDOH. Other organisations can play a fundamental role in supporting the eHealth and mHealth ecosystem.

High-level recommendations for policy-makers and stakeholders that will be important for future implementation are discussed. Other government departments, such as the DOC, also have a duty to ensure the broadband improves by investing in the ICT infrastructure necessary for connectivity in rural areas. Mobile providers and telecommunication companies can ensure prices are lowered for text-messages and data bundles to increase access to online services. This will support NDOH mHealth programmes.

The NDOH could collaborate with other countries who are either already using an evidence-based website or in need of its development. This can be a context-specific platform where information is targeted at patients and health-workers. The designers of eHealth software and mHealth applications can work with the innovating doctors on the ground to develop formalised digital solutions. These can then be commissioned and backed by the NDOH. Other African governments and ministries of health can learn from the South African policy implementation and in particular, its successes and failures. The enablers and barriers to digital communication may be similar in other African contexts with similar levels of eHealth and mHealth maturity. The

WHO and other international bodies, who have an investment in digital communication systems, can use the findings to understand the digital landscape of this middle-income country and decide how this may apply elsewhere. Findings may also aid their key reports, such as when the WHO eHealth toolkit is revised.

The suggested implications for policy give rise to several future research opportunities.

8.7 Future research recommendations

Based on the findings, several areas merit further research. Some of these have been discussed throughout this chapter.

A critique of the 12-point framework used to categorise the eHealth and mHealth examples evident in a rural South African setting

Labrique's *et al.* (2013) framework was useful to categorise mHealth solutions in this thesis. His taxonomy could envisage mHealth opportunities along the continuum of care as in the UNICEF (2015:1) model. It could consider which area of the health system needs strengthening and if so, how digital communication can be part of this strengthening process. Currently mHealth in South Africa has a single solution focused approach. This needs to become integrated across the entire continuum of care (Labrique *et al.*,

2013:160). Figure 30 considers how mHealth solutions might work together as part of an integrated system across the continuum.

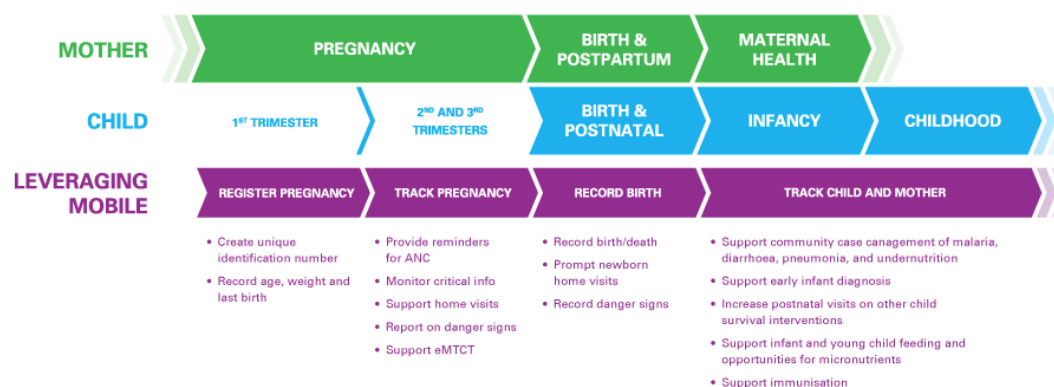


Figure 30. A model of mHealth solutions delivered across the continuum of care designed by UNICEF (2015:1)

The NDOH could use this model to guide how they could incorporate mHealth solutions for patients across the care continuum since they have already leveraged the mobile registration of pregnancies. The same model could apply to patients with chronic disease. Future research could attend to the model to determine where along the continuum mHealth solutions could be used in a South African context. For example, the Vutivi study could not determine the types of patients for which that reminder systems are most useful. Free's *et al.* (2013:18) review found that the effects of mobile technologies remain open to question. This includes which functions (text-messages, video, voice, application software) and which behaviour change techniques are effective. Also whether the effectiveness of interventions are

influenced by the setting or participant demographics needs to be better understood. Research is still needed into the most appropriate technologies for each condition.

Other future research designs

Longitudinal research, to understand the effects of technological change, uptake and usage for different users is necessary. If informal mHealth strategies that are user-driven are taken into account, then the users may be more willing to adopt and adapt to more formal solutions. The effectiveness of health education via digital means to supplement nurse health talks need to be tested. For example, a RCT where the intervention-arm receives educational messages and the control-arm receives only the usual health talks. The intervention could also extend to online adherence clubs, using mobile platforms already in existence. Researchers could also assess the extent to which the Vutivi findings hold true in other rural settings with similar participant groups. Reasons for why there are deep-seated issues of poor management and maintenance need to be better understood in terms of cultural, political, psychological and behavioural perspectives, so these can be addressed and changes made.

eHealth and mHealth maturity over time

The integration of eHealth and mHealth into the health system is not delineated until it matures over time. The government has a very clear understanding of how they want digital communication systems to strengthen their health system. Only ‘watchful waiting’ will determine whether the opportunity of mHealth to support and enable service delivery interventions is effective and at which level (micro/meso/macro). There has been a lack of commitment to address rural technological deficits but this is changing. mHealth can support existing structural inequalities specifically in rural settings. Future studies will need to determine the process of policy implementation over time using ‘health policy analysis’ (Walt *et al.*, 2008:308).

Future theoretical research

Broader theoretical questions remain. For example what is the theory underpinning the use of digital technology for health-workers and the reasons for any failed normalisation. Giddens’s (1984) theory of structuration is described by Kairy *et al.* (2014) as the norms, rules, resources and values that enable or constrain the agent. The agents’ (the patient and health-worker) reasoning that creates action/response is enabled or constrained by the mechanisms/resources of the technology and the context. Assessing the impact of digital solutions in different healthcare environments will be the

government's priority. Without impact in terms of efficiency and improvements, they will need to question the feasibility of future digital health investment. Finally, there needs to be an improved understanding of the unintended and unanticipated consequences of implementing everyday technology such as mobile phones used for different purposes from their intended function. To minimize negative effects, the introduction of new technology within a constrained health system, needs to be monitored.

Although these future research suggestions are beneficial to the improvement of understanding the field of eHealth and mHealth, this research has in itself made important contributions.

8.8 Research contribution

This body of empirical and theoretical research contributes to the field of health system strengthening. The thesis critically explores the potential role for appropriate digital technological solutions in the innovation of health system design, implementation and normalisation in rural South Africa. The analysis has improved current knowledge of how patients and health-workers are using phones and computers to enhance and improve their lives, for health utilisation and service delivery. Several recommendations have also been made for the different stakeholders within the eco-system.

The results may inform policy and programme decisions for the government's future eHealth and mHealth agenda. The main research contributions for each health system level are defined in Table 34.

Table 34. Presentation of three main key research contributions relevant for each participant group

<p><i>Patient level</i></p> <ul style="list-style-type: none"> -An understanding of how chronic patients and how pregnant women are using their phones. <p>This can inform the design and development of mHealth interventions and programmes.</p> <ul style="list-style-type: none"> -Nkateko trial - evidence that phone call reminders for routine clinic appointments from LHW to patient with hypertension are beneficial. -mHealth as a tool for chronic disease management and general patient education is applicable, acceptable and appropriate for many participants. Issues such as eyesight, appropriation of technology, affordability of airtime and lack of consistency in the availability of airtime needs to be considered.
<p><i>Health-worker level</i></p> <ul style="list-style-type: none"> -The use of doctors to help design and innovate – development for and by the doctors as a response to challenges faced. - The training of nurses in computer skills.
<p><i>Community member level</i></p> <ul style="list-style-type: none"> -An understanding of the Internet is still poor but scope for Internet safety training.
<p><i>Policy-Maker and expert level</i></p> <ul style="list-style-type: none"> -Perspectives of the decision makers, designers and implementers about where digital communication systems are being used now and in the future. -Findings contributed to the government's publication of mHealth Strategy.

Beyond its academic contribution, the primary focus of the study was to provide information to policy-makers and other key stakeholders who may invest in digital communication systems to inform services in primary care for patients with chronic conditions and pregnant women. The findings presented in this thesis have already contributed to the NDOH mHealth Strategy and the NHI white paper detailed in Appendix 12.

The contribution to research will be disseminated through different channels as discussed in Chapter 4. The thesis conclusion, in light of the overall results is now presented.

8.9 The Vutivi thesis conclusion

The Vutivi study found that mobile phones are being used in relation to health in varying degrees as their use becomes normalised. There is evidence of mHealth use but it is ad hoc and informal. This illustrates that consumers and providers want to adapt and make use of digital solutions in their everyday lives and clinical work. Informal mHealth occurs amongst patients who are seeking digital health resources and improvising their own digital solutions. These mobile communication channels can foster communication between health-workers and patients. Patients can be the implementers and users of their phones to self-manage. This was also true for nurses' computer use and doctors' smartphone use. However inequities are emerging as result of some patients and health-workers having greater personal access to technology (the

ability to access, to pay and the skills to use the technology). They may access inaccurate information (over social media/Internet) potentially causing risk to the patient if they become reliant on digital means. There is evidence that localised innovation is making a difference to work and health practices. To enable these local innovations to flourish in the future a way forward may be to enhance current digital processes that mediate practice.

To formalise local innovation, greater dialogue between the doctors as the innovators, private companies as the investors and government as the providers is necessary. Development is coming from within. The doctors are initiating development, as they understand their own needs to provide services to patients. They are responding to needs where resources are limited.

With cheaper calls, connectivity and smartphones prices more health-workers will be able to use their personal resources at work, many of whom were already willing to do so. The sacrifice of using personal devices will become commonplace, if it allows for greater ease of access. Nevertheless, systems to ensure that people are not excluded due to airtime affordability will have a significant impact on how and what people can use their phones for. There may be no need to demand massive infrastructural investment from the government at the level of patients and the health-workers if costs are lowered. Other enablers to the success of digital communication systems

include the development of broadband in health facilities under the NHI reform. Greater connectivity is the first step in upholding any eHealth system and mHealth programme. Free Wi-Fi hubs in communities will also be efficacious and help to address digital access inequity. Other enablers involve the improvement of mobile network coverage, interoperability standards, and patient protection and data governance.

Findings suggest that poor communication, access to information and continuity of care are considerably improved for both patients and health-workers when using digital technology. Opportunities to use eHealth and mHealth are evident, particularly in assisting poor communication between facilities leading to stagnant referrals. Sending reminders to patients' phones is unlikely to be interactive since the resource to purchase airtime is limited. Some nurses' access health-information for work purposes on their personal phones with poor validity of retrieved Internet literature. Older patients rely on grandchildren to read messages due to poor eyesight or literacy. Evidence of informal mobile digital communication use needs to be formalised, adapted and built on existing forms of communication. Digital solutions may improve these processes but will not eliminate them. The complexity of digital communication systems requires significant reorganisation of health services and on-going support. This will not solve broader health system challenges.

The use of digital solutions as an intervention within already effective interventions may increase the likelihood of effectiveness.

If the provincial DOH and other departments that also have a stake in ICT all ‘come to the party’, there is a greater chance of success. There was little evidence of coherent collaboration. If budgets are set by the NDOH for digital communication systems then provinces will largely have the same expenditure on allocation of resources. The autonomous power of provinces has been a hindrance to some health reforms. The NDOH is doing early transformational work, laying the foundations for eHealth structures. There needs to be a coalescence of national, political and clinical leadership that filters down to the provinces and districts if digital communication systems are to be successful.

Those in charge of eHealth and mHealth policy need not be concerned about projects being in silos and rather ensure that the top-level overarching enablers are in place, such as reliable broadband and cheaper airtime. Also by considering governance, ethics and training, this will allow for those individual projects to conform to these set standards, naturally aligning their digital models with government’s objectives. It will also allow for patients and health-workers to be innovative and support these digital processes. By continuing to establish the standards for digital communication in health that

the stakeholders can adhere to, the government will then be on the right track for future success of digital solutions.

The NDOH is starting to dynamically mainstream digital communication programmes to assist in strengthening the health system. Part of the NHI's plan is to bridge the structural divide and redistribute resources equally. Digital solutions can be classed as one of these resources. If all mHealth projects are regulated by the South African government and follow the core principles of the mHealth Strategy and Normative Standards, there will be a more coherent and controlled set of programmes. Policy-makers and implementers would benefit from considering broader health system dimensions in scaling-up mHealth. The Vutivi study's extension of the government's Health Systems Framework might assist with such deliberations.

The context of health delivery in low-resource settings is almost ready to embrace digital health solutions. In particular, when the quality of the communication improves and the issue solely revolves around the ability to communicate. This should work if the person is not reliant on current infrastructure, good management, certain skills and technology appropriation. The complexity of this type of technology is only as good as the end-user. Implementation is often complex and the process of normalisation is gradual as mHealth becomes embedded into existing practice and new clinical

routines. The development of the theoretical frameworks and models based on the realist methodology can be used to guide the digital technology implementation.

More ‘substantive mHealth developments’ (Hall *et al.*, 2014:9) need to be realised if the government’s investments are to be reconciled with the achievement of a stronger health system, particularly for rural citizens (Reid, 2006). The case for eHealth and mHealth in rural South Africa remains compelling. The government’s ambitions for NHI will only be realised if they tread vigilantly in the direction of digital communication systems. The public health system has many systemic problems and mobile and non-mobile digital communication technologies will not be a standalone solution. They need to be carefully developed with the end-users and driven by the health-workers. It is also evident that technology use for health is becoming a key element of people’s lives, even in rural settings. Enhancing healthcare through the use of digital technology has potential when its implementation is integrated with normalisation.

As Foucault (1983:63) said ‘my point is not everything is bad, but that everything is dangerous’. The use of digital solutions to assist in the health system may at first appear dangerous but the benefits might potentially outweigh the risks. It would be wise for the South African eHealth and mHealth agenda to move forward with cautious optimism by realising the

caveats and advantages of digital systems in strengthening the country's health system, as this study has demonstrated.

Appendices



Photo 24. A woman showing how she keeps her phone in a pouch around her neck

Appendix 1: Ethical committee approval letters

A. WARWICK – BSREC

Study Number: REGO-2013-82

Full ethical clearance was granted from The University of Warwick on April 23rd 2013 from Warwick Medical School, Biomedical and Scientific Research Committee (BSREC).

B. WITWATERSRAND – HREC

Study Number: R14/49 (M130411)

Full ethical clearance was granted on 26th April 2013 from The University of the Witwatersrand Human Research Ethics Committee - Medical (HREC), Johannesburg, South Africa.

C. PROVINCIAL DEPARTMENT OF HEALTH APPROVAL

Full ethical clearance was granted from the Mpumalanga Province – Department of Health on 7th August 2013 to conduct research in the province.

D. DISTRICT DEPARTMENT OF HEALTH APPROVAL

Full ethical clearance was granted from the Bushbuckridge sub-district – Department of Health on 13th November 2013 to conduct research in the province.

E. STUDY SITE PERMISSION

Permission to undertake research at the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) on was granted on 25th February 2013.

Tuesday 23rd April 2013

Warwick
Medical School

PRIVATE

Jocelyn Watkins
WMS
University of Warwick
Coventry
CV4 7AL

Dear Jocelyn,

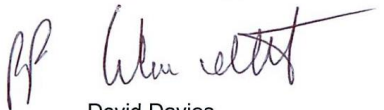
Study Title and BSREC Reference: *A Critical analysis of the potential for innovation in health system design, implementation and normalisation in rural South Africa, including appropriate use of digital and networked technology*, REGO-2013-082

Thank you for submitting your revisions to the above-named project to the University of Warwick Biomedical and Scientific Research Ethics Sub-Committee for Chair's Approval.

I am pleased to confirm that I am satisfied that you have met all of the conditions and your application meets the required standard, which means that full approval is granted and your study may commence.

I take this opportunity to wish you success with the study and to remind you any substantial amendments require approval from the committee before they can be made. Please keep a copy of the signed version of this letter with your study documentation.

Yours sincerely,



David Davies
Chair
Biomedical and Scientific
Research Ethics Sub-Committee

**Biomedical and Scientific
Research Ethics Subcommittee**

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Coventry, CV4 7AL.
Tel: 02476-151875
Email: A.C.Ismay@warwick.ac.uk



M130411

R14/49 Jocelyn Watkins

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130411

NAME: Jocelyn Watkins
(Principal Investigator)

DEPARTMENT: Division of Health Sciences
University of Warwick

PROJECT TITLE: A Critical Analysis of the Potential for Innovation
i Health System Design, Implementation and
Normalisation in Rural South Africa, Including
the Appropriate Use of Digital and Networked
Technology

DATE CONSIDERED: 26/04/2013

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR:

APPROVED BY:

Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 08/07/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature _____

Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

MPUMALANGA PROVINCIAL GOVERNMENT

Building No.3
No. 7 Government Boulevard
Riverside Park Extension 2
Nelspruit
1200
Republic of South Africa



Private Bag X 11285
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Department of Health

Litiko Letemphilo

Umnnyango WezaMaphilo

Departement van Gesondheid

Enquiries: Themba Mulungo (013) 766 3511

07 August 2013

Mrs Jocelyn Watkins
Warwick Medical School
The University Of Warwick
United Kingdom
COVENTRY
CV4 7AL
UNITED KINGDOM

Dear Mrs Jocelyn Watkins

**APPLICATION FOR RESEARCH & ETHICS APPROVAL: A CRITICAL ANALYSIS OF THE
POTENTIAL FOR INNOVATION I HEALTH SYSTEM DESIGN, IMPLEMENTATION AND
NORMALISATION IN RURAL SOUTH AFRICA, INCLUDING THE APPROPRIATE USE OF
DIGITAL AND NETWORKED TECHNOLOGY**

The Provincial Research and Ethics Committee has approved your research proposal in the latest format that you sent.

Kindly ensure that you provide us with the soft and hard copies of the report once your research project has been completed.

Kind regards


Dr. William R.M Maphanga
Chairperson PHREC

7/8/13
Date



MPUMALANGA PROVINCIAL GOVERNMENT

R563 Hazyview
Kruger National
Park Road
Hoxani Multi-purpose Centre
Mkhuhlu
1246



Private Bag x 3009
MKHUHLU
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Department of Health BUSHBUCKRIDGE HEALTH SUB-DISTRICT

Ndzawulo Ya Rihanyo

Umnvango WezaMaphilo

Departement van Gesondheid

Enq: Mtungwa I.L.
013 708 0046

13th November 2013

Vutivi (Health Technology) Study – MRC/Wits Agincourt Unit

The above study has been reviewed by me (the Deputy Director-PHC) and has been given the go ahead. The study will be run in the clinics in January/February 2014.

Please ensure that the researcher, Mrs Jocelyn Watkins, gives you a copy of the short protocol and the Mpumalanga Department of Health ethical approval letter when she makes arrangements to come to work in your clinic.

Yours faithfully,

Mr Ishmael Mtungwa

School of Public Health
University of the Witwatersrand

7 York Road
Parktown 2193
Tel: +27-11-717 2085
Fax: +27-11-717 2084



25 February 2013

Dear Colleagues

Permission to undertake research in the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt)

Jane Goudge (PhD), Frances Griffiths (PhD), and Jocelyn Watkins (MSc) are planning research in the Agincourt sub-district and MRC/Wits-Agincourt research centre, north-eastern South Africa, entitled, "A critical analysis of the potential for innovation in health system design, implementation and normalisation in rural South Africa, including the appropriate use of digital and networked technology."

The purpose of the proposed research is:

1. To explore technologies that have the potential to enhance healthcare. It aims to investigate what the policy barriers are to technological implementation and what the significance of such technologies are to the local community.
2. To better understand the usage, applicability, acceptability and appropriateness of digital ICT for the provision of PHC and support of self-care for patients with chronic conditions. Data analysis will assess provider/user attitudes and experiences of ICT technologies.

Jane Goudge, Frances Griffiths, and Jocelyn Watkins are encouraged, and have my permission, to undertake this research in the MRC/Wits-Agincourt Unit working together with the Agincourt Research Manager and scientist, Dr Xavier Gómez-Olivé.

The proposed research is important for extending the research agenda in Agincourt and the findings should significantly advance our efforts to understand which new technologies can be used in the rural clinics to better serve the users of these facilities. Similarly, findings will inform PHC service development.

Please do not hesitate to contact me should you require any further information.

Yours faithfully

A handwritten signature in black ink, appearing to read "Stephen Tollman".

Stephen Tollman MMed, MPH, MA, PhD
Director, MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt)
Head, Health and Population Division, School of Public Health, University of the Witwatersrand

Appendix 2: Realist review example CMOc tables for a sample of empirical studies

Mbuagbaw (2012) - Cameroon - HIV

Context		Technical Mechanism	Patient action	Outcome
HIV patient been taking ART for more than one month (experienced patient)	Patient owns a mobile phone and can use phone	Weekly Motivational (1/11 variations) SMS sent by research team (not clinician) as motive statement to patient	Patient does not need to reply. Patient changes behaviour accordingly based on motive statement recommendation (change in behaviour is not enough to change adherence to ART)	Standardized motivational mobile phone SMS did not significantly improve adherence behaviour to ART among experienced patients (after 6 months)
HIV patient been taking ART for more than one month (experienced patient)	Patient owns a mobile phone and can use phone	Weekly Motivational (1/11 variations) SMS sent by research team (not clinician) as motive statement to patient	Patient does not reply	Patient continues normal behaviour or defaults drug regime
		Weekly Cue to Action direct Medication Reminder SMS	Triggers patient to take medication because of receiving message	Patient adheres to ART regime. No significant effect of motivational SMS texts on improving adherence to ART
		Weekly Cue to Action direct Medication Reminder SMS	Patient does not take medication or Patient takes medication anyway despite reminder message	No change in behaviour (Patient adheres or not to ART regime)
		Weekly Reminder SMS including support line number they can contact	Patient uses helpline/support	SMS may be more effective in treatment-naïve population – shorter duration on ART




		Weekly Reminder SMS including support line number they can contact	Patient does not use recommended helpline/support	Enhanced communication channels available but not used. Patient has to pay for the SMS or call to the physician.
Health system can't always supply drugs		Reminder SMS to take drugs	Patient can't take drugs because of stock out (health system rather than human error)	Patients don't adhere to ART treatment

Rotherum-Borus (2012) – South Africa - Diabetes

Context		Technical Mechanism	Patient action	Outcome
Patients routinely taking medication	Diabetes buddies to offer peer support	Different SMS probes sent daily about adhering to a healthy lifestyle	Patient reads message probe, understands content and monitors their eating and walking	Patient blood glucose level improves through behaviour change. Does not change behaviour related to diabetes significantly. Positive effect on sleep.
Patient education about self care for diabetes is minimal	Diabetes buddies to offer peer support	Different SMS probes sent daily about adhering to a healthy lifestyle	Patient does not read content probe and/or Patient does not monitor their eating and walking	Patient feels accountable to someone
Patient education about self care for diabetes is minimal	Diabetes buddies to offer peer support	Patient can reply to SMS	Patient replies to SMS	Patient feels empowered and that someone cares and greater optimism for them so adopts change in behaviour.

				Women responded only 54% of the time. Positive effect on coping.
Patient education about self care for diabetes is minimal	Diabetes buddies to offer peer support	Patient can reply to SMS	Patient does not reply to SMS	No change in behaviour
Patient education about self care for diabetes is minimal	Diabetes buddies to offer peer support	Information sent by trained buddies, via SMS to patient about lifestyle change	Patient responds via SMS or voice to buddy for extra support	Increased quality and frequency of peer support. On average 123 text exchanged between patient and buddy per week.

Appendix 3: Research poster displayed in clinics in English and Xitsonga



FACILITY OBSERVATION IN PROGRESS

TO ALL STAFF, PATIENTS AND VISITORS: VUTIVI PROJECT

This facility is currently being observed by Mrs Jocelyn Anstey Watkins, a researcher from the University of the Witwatersrand and Warwick Medical School.

This observation is part of a research project looking at the use of digital and networked technologies (e.g. cell phones, internet) for patients with long-term chronic conditions and antenatal women within healthcare clinics. Observations will include the day-to-day functioning of the facility and interviews with staff and patients.

Jocelyn may approach you to have an informal conversation about what has been observed. In talking in this informal way, she will be sensitive to the time pressures and other commitments of the person she is speaking to. Jocelyn may also ask your permission to have a more formal interview, which should take between 45-60 minutes, either before or after your appointment/shift. If this happens, she will ask you for written informed consent, along with consent to tape-record the interview.




Jocelyn may also approach you to be observed during a consultation with a healthcare professional/patient. In this case, again you will be asked for signed consent. This will not be tape-recorded.

It is entirely up to you whether or not you agree to talk to Jocelyn or be observed during a consultation. It is your right to refuse and this will not impact on the healthcare that you receive in any way.

The names of facilities and individuals observed will not be used in the research report. We will keep all information that people provide confidential.

Permission to carry out this project has been obtained from the MRC/Wits Agincourt Unit and The Mpumalanga Research Committee, as well as the District Management of the health facility. Ethical approval for has been obtained from The University of Warwick 'Biomedical and Scientific Research Ethics Committee' (BSREC) and the University of the Witwatersrand Ethics Committee for Research on Human Subjects (Medical).

If you have any concerns, questions or complaints you can contact the Project Site Manager (see his contact details below). Please note this is only a descriptive study whereby, the researcher is only exploring how the use of digital and networked technologies can improve care for patients with chronic conditions and antenatal women. Therefore this is not a research trial and does not require any invasive medical testing of the individual. Jocelyn is interested in learning more about what could be implemented in the future to help improve the functioning and delivery of healthcare services by using digital and networked technologies, which is part of the government's e-Health strategy.

THANK YOU		INKOMU SWINENE	
Project Site Manager		Dr Xavier Gómez-Olivé (English speaking contact) MRC/Wits Agincourt Unit offices Tintswalo Hospital, Acornhoek Tel: 27-13-795-5076, Cell: 076-378-8255 Audrey (Xitsonga speaker)	
If you are worried about anything to do with this study, you can contact the chair of the ethics committees: Prof. Peter Cleaton-Jones (University of the Witwatersrand). Tel: (011) 717-2301			
<div><div></div><div></div></div> <p>KU HLALERIWA KA NDHAWU LOKU NGA LE KU ENDLEKENI</p> <p>EKA VATIRHI HINKWAVO, VAVABYI XIKAN’WE NA VAENDZI: VUTIVI PROJECT</p> <p>Ndhawu leyi yi le ku hlaleriweni eka nkarhi wa sweswi hi Mrs Jocelyn Anstey Watkins loyi a nga mulavisisi ku huma eka Yunivhesiti ya Witwatersrand xikan’we na Xikolo xa Vudokodela xa Warwick</p> <p>Ku hlalela loku i xiphemu xa ndzavisiso lowu nga le ku hlaleleni ka matirhiselo ya thekinoloji ya vuhlanganisi (e.g. tiqingho ta le nyongeni, “internet”, vukamberi bya le ndzeni eka ku biha emirini) eka vavabyi lava nga na mavabyi ya nkarhi wo leha lawa ya nga tshungulekiki xikan’we na vayimani lava nga kona eka tikliniki leti nyikaka mphakelo wa swarihanyu. Ku langutisisa loko ku ta katsa matirhelo ya ndhawu ya siku rin’wana na rin’wana na mimbhurisano ni vatirhi xikan’we na vavabyi.</p> <p>Jocelyn u ta tihlanganisa na n’wina ku va mi burisana hi swilo leswi hlaleriweke. Ku va mi burisana hi ndlela leyi yo ka yi nga ri ya ximfumo, u ta tekela enhlokweni ku tikeriwa loku nga kona eka nkarhi xikan’we na swilo leswi munhu loyi a burisanaka na yena a nga na swona. Jocelyn a nga tlhela a kombela mpfumelelo wo va na mbhurisano ximfumo na n’wina lowu nga ta teka kwalomu ka timinete ta 45 – 60, ku nga ha va loko mi nga si sungula kumbe loko mi hetile ntirho wa n’wina kumbe mi va mi kumile ku pfuneka. Loko leswi swi ri ku endlekeni, u ta mi kombela leswaku mi n’wi nyika mpfumelelo lowu tsariweke xikan’we na mpfumelelo wo kandziyisa mbhurisano.</p> <p>Jocelyn u ta tlhela a mi kombela ku va a ya hlalela hi nkarhi lowu vaka mi kuma ku pfuniwa hi swarihanyu loku vaka kona exikarhi ka muvabyi na muongori. Eka xiyimo lexi, mi ta tlhela mi komberiwa ku nyika mpfumelelo hi ku sayina. Leswi a swi nga kandziyisiwi.</p> <p>Swi le ka n’wina loko mi ta va mi tsakela kumbe mi nga swi tsakeri leswaku Jocelyn a burisana na n’wina kumbe ku hlalela hi nkarhi lowu mi kumaka ku pfuniwahi swarihanyu. I mfanelo ya n’wina ku va mi ala naswona leswi swi nga ka swi nga</p>			

khumbi helo mpfuno wa swarihanyu lowu mi wu kumaka, hi ndlela yihi kumbe yihi.

Mavito ya ndhawu xikan'we nay a vanhu lava nga ta hlaleriwa ya nga ka ya nga tirhisiwi eka rhipoto ya vulavisisi. Hi ta hlayisa vuxokoxoko hinkwabyo lebyi vanhu va hi nyikaka byona byi va xihundla.

Mpfumelelo wo endla ndzavisiso lowu wu kumiwile ku suka eka yuniti ya MRC/Wits Agincourt na Komiti ya mindzavisiso ya Mpumalanga, ku katsa na le vurhangeri bya xifundzha-ntsongo xa tindhawu ta rihanyu. Mpumelelo wa swamilawu wu kumiwile ku suka eka Yunvhesiti ya Warwick 'Biomedical and Scientific Research Ethics Committee' (BSREC) na Komiti ya Swamilawu ya Vulavisisi na Vanhu ya Yunvhesiti ya Witwatersrand (Vudokodela).

Loko mi ri na swivilelo, swivutiso kumbe swisolo mi nga tihlanganisa na murhangeri wa le sayitini wa ndzavisiso lowu (vonani vutihlanganisi bya yena laha hansi). Tekelani enhlokweni leswaku ndzavisiso lowu ko va vuhumelerisi lebyi mulavisisi a nga le ku lavisiseni hi vuenti ndlela leyi thekinoloji ya vuhlanganisi yi nga antswisaka ha yona mpfuno eka vavabyi lava nga na mavabyi lawa ya nga tshungulekiki na vayimani. Tivani leswaku a hi ndzavisiso wo ringeta naswona a wu lavi swikambelwana swarihanyu leswi endliwaka na munhu. Jocelyn u tsakela ku dyondza swot ala mayelana na leswi nga endliwaka eka nkarhi lowutaka ku pfuna ku antswisa matirhelo xikan'we na ku nyikiwa ka vukorhokeri bya swarihanyu hi ku tirhisa thekinoloji ya vuhlanganisi leswi ku nga xiphemu xa Mfumo xa maendlelo ya e-Health.

INKOMU SWINENE

Project Site Manager

Dr Xavier Gómez-Olivé (English speaking contact)
MRC/Wits Agincourt Unit offices
Tintswalo Hospital, Acornhoek
Tel: 27-13-795-5076, Cell: 076-378-8255

Loko mi vilerisiwa hi swin'wana na swin'wana leswi fambelanaka na ndzavisiso lowu, mi nga tihlanganisa na mutshama-xitulu wa komiti ya swamilawu: **Prof. Peter Cleaton-Jones** (University of the Witwatersrand). Tel: (011) 717-2301

Appendix 4: Observational check list for clinics and hospital

Healthcare Clinic: Observation Framework and Checklist Tool

This observational framework has been adapted from Dr J. Goudge, Dr. F. X. Gómez-Olivé and Prof. M. Thorogood's situational analysis for the Nkateko study with their permission. Its purpose is to act as a checklist tool to be used during observations in the healthcare centres/clinics/hospitals. I will liaise with the fieldworkers on Nkateko study to ensure complementarity of fieldwork, to avoid access burden on the health services, staff and patients.

The aim of observations for the digital and networked technology study is to determine use and potential future use of digital and networked technologies in primary healthcare settings for and by healthcare staff (nurses/doctors/community health-workers) and both chronic condition and antenatal patients.

Mrs Jocelyn Anstey Watkins will undertake all observations.

<i>OBSERVATION FRAMEWORK</i>		
1. Name of healthcare facility		
2. Type of healthcare facility	Healthcare Centre/Clinic	Health centre
3. Date of observation		
4. Name of person making observations		
<i>OBSERVERS Notes</i>		
<ul style="list-style-type: none"> • This tool includes a list of issues I will need to consider in the observation. I will write detailed descriptions of what I see along with answering the questions below. Detailed field notes will be kept for each observational visit. • During the observations, detailed attention will be paid to the 'who, what, where and when' of the different processes taking place at the facility. A detailed description of the steps an average patient goes through from arrival at to leaving the health facility will be made. <i>The what</i>, with whom, where and when should be derived from observing several individual patients and should be summarized, e.g. in tabular form. In particular, I will look for digital and networked technology in use or areas where potential for use is apparent. 		

- After these more general observations, the focus of the observation should shift to the interactions between people in the facility (providers and patients, providers and each other, patients and each other). After these more general observations, I will look for digital and network technologies.
- This is not just a questionnaire. Rather, it is a set of categories/themes to guide the observation process, i.e. what to “look at” in terms of relationships, interactions and dynamics between people and people and technology.

What will be observed?

PHYSICAL SPACE

Physical layout of the facility (here, it can be useful to draw a sketch of the layout of the facility):

Exterior:

- Accessibility of clinic
 - Public transport, taxis, walking distance from closest taxi drop-off point
 - Opening hours on sign post, gated access, presence of security guards
 - Physical barriers for people with disabilities –
 - ICT accessibility by phone/web –
- General environment:
 - Cleanliness, lighting, specific waiting/ seating area
 - Are there amenities nearby (toilets, drinking water, place to buy food?).
 - Cell phone connection? Which providers?
 - Reliability of electricity -

Interior:

- Description of the layout of the facility
 - How is the interior space structured? What is the overall impression (e.g. dirty/clean; bright colours/dark, gloomy; patient-friendly or intimidating; etc.)?
 - Is it easy to find the relevant treatment area?
 - Is there a designated waiting area? Are people left standing or queuing outside?
 - Are the reception and information desks arranged so the patient has privacy?
 - Is there clear sign posting?

- Where do the consultations take place? Are they private or public?
- Where is the digital and networked technology stored?
- Where is the digital and networked technology used? By the data clerk, the doctor and the admin office.
- Chronic condition-related information/antenatal health related-information
 - Are there any posters, signs, directions, etc?
 - What topics do they address?
 - Are these displayed visibly?
 - Are there Complaints Boxes and are they accessible to patients?
 - Are there any email/telephone or web addresses on any of the information?
- What languages are they in? Do they use clear graphics?

GENERAL CLINIC OPERATION

What time does the clinic open? (*Actual rather times on notice board*)

Numbers of nurses present that day?

Number of nurses in chronic disease treatment room (s) for chronic conditions patients?

Number of nurses in antenatal consulting room (s) for antenatal women?

Are there any CHWs at the clinic? How many?

What are their activities?

What types of machines are there?

Is maintenance a problem?

Is there a computer?

Is maintenance a problem?

If so, what is it used for?

Does the clinic and staff have mobile phones - who owns them/how are they maintained?

Are they used for clinic purposes (ordering drugs etc.)?

DRUG SUPPLIES

The justification for finding out if the clinic has the correct drug supplies is because e-health could play a role in improving this process.

How are the drugs ordered (with technology in mind)?

What is the process for ordering the drugs?

How are the drugs ordered?

How are the drugs stored?

How are the drugs distributed?

How is the stock control of the drugs taken/recorded?

Whose responsibility is this?

DESCRIPTION OF THE CHRONIC DISEASE AND ANTENATAL QUEUING AND FILING SYSTEMS

- Are patients' files pulled out prior to the patient's arrival?
- Are files filled back again the same day?
- Are there problems with the filing system that you can see?
- Are medications prepared in advance of routine checks? If yes, for which conditions? (HIV, TB, Diabetes, Hypertension)
- Describe main elements of a single chronic disease file/antenatal records?
- Do patients carry anything in which their health data is recorded? If yes, describe what. Have you seen anyone writing in it or looking at it?
- Are computers used for patient data? For all patients, or only HIV patients?
- Is there are different system for antenatal health?

DESCRIPTION OF USE AND FUTURE USE OF DIGITAL AND NETWORKED TECHNOLOGY

What digital and networked technology exists? What is visible? If it is not visible, make a note to ask a member of staff if it does exist.

Or if the technology has been newly implemented, is there a different reaction.

If the technology does not exist - what would have to change (look for areas of where changes can be made and technology implemented?

Try to understand and identify what the additional burden would be?

Try to determine, if there is the potential for a type of digital or networked technology to have a place and use in that setting? Give examples.

One day observation of the Chronic Disease Queue

Today's date and day of the week/...../.....
Is there an appointment list for today?	Yes / No
If Yes, how many names are on the list?	
If you can identify them on the list, how many patients have come for management of hypertension?	
How many patients have come for management of anti-retroviral therapy?	
How many patients have come for management of diabetes?	
How many patients have come for management of TB? (Not including those who have also come for management of anti-retroviral therapy)	
How many patients are in the queue one hour after opening?	
How many patients are in the queue at 11am?	
How many patients who were on the appointment list did not come today?	

If you can identify them on the list, how many hypertension patients didn't come?	
How many HIV patients didn't come	<i>If they got a text-message they may have remembered to come to their appointment for instance</i>
How many diabetic patients didn't come?	
How many TB patients didn't come?	
What other chronic disease patients attended a clinic	List chronic diseases (communicable and non-communicable)

One day observation of the Antenatal Queue

(Please complete one of these forms for each antenatal clinic day)

Today's date and day of the week/...../.....
Is there an appointment list for today?	Yes / No
If Yes, how many names are on the list?	
How many women are in the queue one hour after opening?	
How many women are in the queue at 11am?	
How many women who were on the appointment list did not come today?	

How many women were in the last trimester?	
How many women came to give birth?	
How women brought other children with them?	
How pregnant women had a test for HIV?	
How many of the women had a cell phone on them?	
How many women brought a family member or friend for support?	

OBSERVATION OF CONSULTATION WITH CHRONIC DISEASE PATIENTS

Please complete this checklist for 5 consultations with chronic disease patients

	Patient 1	Patient 2
1. Brief description of patient (gender, age, chronic condition)		
2. Whether and who measures/take tests; e.g. finger print for blood/blood pressure/weight/blood glucose, urine		
3. Where is this information recorded		
4. Whether patient was told reading/results		
5. Whether the reading/result is explained to the patient		
6. Relevant advice is given		
7. Medication		
8. Whether a return appointment is booked		

Please complete this checklist for 5 consultations with antenatal women

	Patient 1	Patient 2
1. Brief description of patient (age, stage or pregnancy)		
2. Whether and who measures/take tests; e.g. finger print for blood/bp/weight/blood glucose, urine		
3. Where is this information recorded		
4. Whether patient was told reading/results		
5. Whether the reading/result is explained to the patient		
6. Relevant advice is given		
7. Medication		
8. Whether a return appointment is booked		

THE NATURE OF THE INTERACTION: Between patient and health-workers

1. How do staff members treat patients in general?
2. How do they speak to patients (friendly, rude, dismissive, attentive, flirtatious, respectful, courteous)?
3. Do they use the patients' language?
4. What is their tone of voice?
5. What body language do they use (open, closed, facial expressions, eye contact, physical distance between patient and provider)?
6. Was there any eye contact?
7. How would you describe the patient and providers facial expressions
8. Would the patient have felt that the nurse was concerned about their health? Please explain

THE NATURE OF THE INTERACTION: Amongst health-workers in relation to the patient

1. Do staff members speak about the patient(s) to each other in a particular way (with respect, quietly, loudly, mockingly, dismissively)?
2. Do staff members use the same amount of time on all the patients?
3. Do staff members ignore patients/prioritise other tasks when they are together?

THE NATURE OF THE INTERACTION: Amongst health-workers in general

1. What is the overall mood amongst the staff?
2. Do they interact as part of a team or in a disconnected way?
3. Do the staff members support and cooperate with each other?
4. How do junior staff members engage with their seniors (relaxed, confident, afraid)?
5. How do senior staff / managers engage with their juniors/subordinates (punitive, encouraging, confidentially, professionally)?
6. How are the non-professional staff treated by other staff members?
7. How do providers address each other? Are some people called “sister”, “doctor” while others are called by their first names?

DAILY TASKS

How do people go about their jobs on a day-to-day basis (with diligence, calmly, carelessly, distractedly?).

1. Do staff members seem happy, willing, resentful, disinterested, and afraid?
2. How often do staff members take breaks? How long are these breaks? Do they take them at the same/different times?
3. How busy do providers seem to be? Are they all equally busy? Are they busy at certain times, or the whole day?
4. Are staff members given ‘freedom’ to conduct their duties in an uninterrupted way or do supervisors interrupt arbitrarily?
5. Who uses technology? Which members of staff?
6. What technology is used?
7. What is it used for?
8. What everyday tasks do nurses use the technology for?
9. Is it problematic to use technology? Or does it look like it is normalised in every day practice? They do try to utilise what is available. It is problematic if they are not trained.
10. Is there technology available, which is not being used?

11. What are the reasons that this technology is not being used (judging from the observations).

OTHER OBSERVATIONS

Technology

1. Particularly think about the types of technologies currently in use or what could be used in the future.
2. About the context/the time taken to do some processes/the processes and interactions/the actors involved.
3. What technologies (e.g. cell phones/computers) are used? Who uses them?
4. Does clinic staff use them for personal use when at work?
5. Are they having conversations on their own mobile phones or on the work landline phones?
6. Other observations about technologies.
7. Is the technology there but not being used?

Appendix 5: Consent forms for participants in Xitsonga and English



Length of interview:

Clinic ref:

PAPILA RA MPFUMELELO

Nhloko-mhaka ya ndzavisiso: Vutivi Project (Ndzavisiso hi thekinoloji ya rihanyu)

Warwick Biomedical and Scientific Research Ethics Committee Study Number: REGO-2013-082.
Witwatersrand Health Research Ethics Committee Study Number: M130411

Mavito ya mulavisi/valavisi: Mrs Jocelyn Anstey Watkins (Primary Investigator), Prof. Frances Griffiths, Dr Jane Goudge and Dr Xavier Gómez-Olivé

Nomboro yo tivisa mungheneleri:.....(Mulavisi u fanele ku tsala)

Hi kombela leswaku u vekela nkomiso wa mavito ya wena eka swibokisana leswi faneleke kumbe ku tirhisa nkandziyiso wa rintiho. Hi kombela leswaku u nga tsali nchumu loko u nga pfumeli ku nyika mpfumelelo.

1. Ndzavisiso lowu wu hlamuseriwile eka mina naswona ndzi kumile nkarhi wo vutisa swivutiso. Ndzi twisisa xihungwana xa vuxokoxoko xa mungheneleri lexi tsariweke February 2013 xa ndzavisiso lowu nga laha henhla.	<input type="checkbox"/>
2. Ndza swi twisisa leswaku ku nghenela ka mina i ku tsakela/tinyikela naswona ndzi tshunxekile ku tihumesa eka nkarhi wun'wana na wun'wana handle ko nyika xivangelo xo karhi na ku va timfanelo ta mina ti nga khumbeki helo.	<input type="checkbox"/>
3. Ndzi pfumela ku nghenela hi ku va ndzi vutisiwa swivutiso	<input type="checkbox"/>
4. Ndza pfumela leswaku vuxokoxoko bya mina bya mbhurisano byi hlanganisiwa na vuxokoxoko lebyi kumiweke eka nkarhi lowu nga hundza hi va Agincourt.	<input type="checkbox"/>

<p>5. <u>Ndza pfumela leswaku mbhurisano lowu wu kandziyisiwa.</u> <u>Ndza swi twisisa leswaku nkandziyiso wa kona wu ta</u> <u>cukumetiwa emakumu ka ndzavisiso.</u></p> <p>6. <u>Ndza pfumela leswaku ku nga va na loyi a hlalelaka ku</u> <u>kuma mpfuno wa swarihanyu, loko ndzi komberiwile.</u></p>	<div style="text-align: center;"> <input type="checkbox"/> <input type="checkbox"/> </div>
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Ndza swi twisisa leswaku ndzi nga cinca mihleketo nkarhi wun'wana na wun'wana naswona
swi nga ka swi nga ndzi khumbi helo.

Nsayino wa mungheneleri: _____ **Siku:** _____

Vito ra mungheneleri: _____ **Nkarhi** _____
(tsala vito ra wena swi vonaka)

Ndza tiyisisa leswaku mungheneleri u twisisile xiyimo na xikongomelo xa ndzavisiso xikan'we
na mpfumelo wo ngenela eka ndzavisiso lowu. U nyikiwile nkarhi wo vutisa swivutiso leswi
hlamuriweke hi ku hetiseka.



Nsayino wa mulavisisi 1.: _____ **Siku:** _____

Vito ra mulavisisi: _____ **Nkarhi** _____
(tsala vito ra wena swi vonaka)



Nsayino wa mulavisisi 2.: _____ **Siku:** _____

Vito ra mulavisisi: _____ **Nkarhi** _____
(tsala vito ra wena swi vonaka)



Length of interview:

Clinic ref:



CONSENT FORM

Title of Project: Vutivi Project (Health Technology Study)

Warwick Biomedical and Scientific Research Ethics Committee Study Number: REGO-2013-082.

Witwatersrand Health Research Ethics Committee Study Number: M130411

Name of Researcher(s): Mrs Jocelyn Anstey Watkins (Primary Investigator), Prof. Frances Griffiths, Dr Jane Goudge and Dr Xavier Gómez-Olivé

Participant Identifier Number: (for the researcher to fill out)

Please initial the appropriate boxes or use an inked thumbprint. Please leave blank if you do not agree to consent.

1. The study has been explained to me and I have had time to ask questions. I understand the participant information leaflet dated February 2014 for the above study.	<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my rights being affected.	<input type="checkbox"/>
3. I agree to taking part by being interviewed.	<input type="checkbox"/>
4. I agree that my interview data can be linked to my previously collected Agincourt data	<input type="checkbox"/>
5. I agree to the interview being audio-recorded. I understand the audio-recording will be destroyed at the end of the study.	<input type="checkbox"/>

6. I agree to being observed in the consultation, if asked.	<input type="checkbox"/>
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I understand that I can change my mind at any stage and it will not affect me in any way.

Participant's Signature: _____ **Date** _____
Participant's Name: _____ **Time:** _____
(please print name)

I certify that s/he has understood the nature and the purpose of the study and consents to the participation in the study. S/he has been given opportunity to ask questions which have been answered satisfactorily.

Researcher's Signature: _____ **Date** _____
Researcher's Name: _____ **Time:** _____
(please print name)

Fieldworker's Signature: _____ **Date** _____
Fieldworker's Name: _____ **Time:** _____

Appendix 6: Basic patient demographic information



Patient Demographic Information for the Vutivi study

Link to Agincourt census database
Participant Study no.



Name	
Surname	
Other name	
Gender	MALE / FEMALE
Date of Birth/...../.....
Cell Phone numbers	
Next of Kin	
Village	
Chronic Disease type	
Antenatal No of months Pregnant	

Appendix 7: Patient information leaflet, letter and guidance



PARTICIPANT INFORMATION LEAFLET, LETTER & GUIDANCE

Title: Vutivi Project

Study Title: Healthcare system design and the integration of digital and networked technology in primary healthcare settings in rural South Africa: a critical analysis.

Research Team: Mrs Jocelyn Anstey Watkins (Primary Investigator), Prof. Frances Griffiths, Dr Jane Goudge and Dr Xavier Gómez-Olivé

Sponsors: The University of Warwick and University of the Witwatersrand

Funders: Economic Social Research Council and GE Healthcare Ltd., UK

Contact Details:

Mrs Jocelyn Anstey Watkins

Tel: 078 27 36 414 E-mail: j.o.t.a.watkins@warwick.ac.uk

Dr Xavier Gómez-Olivé (day time and after hours contact)

MRC/Wits Agincourt Unit offices, Tintswalo Hospital, Acornhoek

Tel: 27-13-795-5076 Cell: 076-378-8255

Letter to Participants

February 2014

Dear Sir or Madame,

The research team at the MRC/Wits Agincourt Unit, University of the Witwatersrand, is running a study to understand the role of networked technology (e.g. cell phones, Internet) in healthcare. I am a member of the team and would like to invite you to take part in this study.

The purpose of this research study in which you are being asked to participate, is to collect information needed to understand whether networked technology is beneficial to primary healthcare facilities service delivery for patients with chronic conditions in the Agincourt field site (all the villages in Bushbuckridge that the MRC/Wits Agincourt Unit works in).. Therefore, during the interview, you will be asked questions about your attitudes to networked technologies and any experiences you have had with them.

In this study we will interview about **50 people with a chronic condition**. You have been selected because you are a patient with a chronic condition (we know this because you

were in the chronic disease queue at the health centre/clinic/hospital). As the researcher, I have not and will not have access to your health records. Before agreeing to participate, it is important that you read/listen and understand what the study will require from you.

If you decide to take part in this study, you will have to sign/thumb-print a separate informed consent document. You will be given a signed copy to keep.

The time required for your participation will be about 20-30 minutes. The interview will be audio-recorded, if you have given me consent to do so. When your interview is typed up, all identifying names will be removed. The interview will be conducted in English, unless you wish to speak to me in xiTsonga through an interpreter. I will interview you either at the health facility when you are there having an appointment. The interview will not disrupt your appointment. If this is not convenient, I can come to your home/village on a date and time convenient to you.

If you agree, we will link your interview data to your data in the MRC/Wits Agincourt Unit database – this is data we collect in the census we do every year in every village in the Agincourt field site. If you consent to this, please be aware that this gives me permission to access all previously collected data on you, for example your education status. This is only going to be possible if you live in one of the villages that are in the Agincourt fieldsite.

You may be asked if I can sit in on your consultation to do an observation. This observation will help us to understand the service that is currently provided. I will ask for both yours and the nurse's consent. I am not clinically trained, so will not intervene in any way. The consultations will not be audio recorded. I will make a few notes. No one will be identified by name in the notes.

If you have any questions, please ask Dr Gómez-Olivé or myself. Thank you for reading this letter of invitation to participate.

Best,



Jocelyn Anstey Watkins

Further Information Vuxokoxoko ku visa emahlweni

- Participation is entirely voluntary. You can withdraw from the study at any time.
- Your data will be strictly confidential. You will not be identifiable in the final results.
- There are no known disadvantages, side effects or discomfort to taking part in the study.
- There are no direct benefits to taking part but research findings will hopefully lead to new health policies to improve the healthcare system.
- There are no financial incentives for taking part.
- The results of the study will be disseminated to the community through the LINC (community engagement) office, once the study is completed.
- The Mpumalanga Province Research Committee, The University of the Witwatersrand and The University of Warwick Ethics Committees have reviewed this study.
- Should you need to complain, please contact: Prof. Peter Cleaton-Jones (University of the Witwatersrand Ethics) Tel: (011) 717-2301.

Appendix 8: Coding framework for empirical data

Code Name	Definition (<i>code description related to RQ</i>)
Current (ACTUAL) use of mHealth between patient and health professional	<p>Actual descriptions/examples of use of the technologies including context, barriers etc. Examples of phone/computer use, Internet and apps use. Current digital activity at the clinics/hospitals. What digital clinical communication works now (or doesn't work) – what are the reasons for this. Include social enablers – e.g. Health professional/patient IT literacy. Description of how phones are being used for everyday and also for health. Networks family/professional – informal and formal mHealth use. IT literacy of younger generation. Social Enablers - Health professional/patient IT literacy. Description of how phones are being used for everyday and also for health. Networks family/professional – informal and formal mHealth use. IT literacy of younger generation. Barriers Adapting to change, new technologies, adoption and adaption Communication between Patients and Health Professional</p>
Current use of mHealth between health professional and health professional/health service	<p>This includes management (as above) Communication between Health Professionals</p>
Future (POSSIBLE/POTENTIAL) use of mHealth between patient and health professional	<p>Potential descriptions and examples of the uses of technologies including context, barriers etc. Examples of where phone/computers/devices could be used (but are not at the moment). Examples of where people have discussed where mHealth could play a role and why it would be helpful or not helpful. In terms of capability, motivation, opportunity, behavioural aspects of technology use. Social Enablers - Health professional/patient IT literacy. Description of how phones are being used for everyday and also for health. Networks family/professional – informal and formal mHealth use. IT literacy of younger generation. Barriers</p>

	Communication between Patient and Health Professionals
Future use of mHealth of between health professional and health professional/health service	As above (including management) Communication Health Professionals
Non future - use of technology	They want to use it in the future but there is a barrier (give example) Where someone talks about wanting to use it but can't because of a barrier (this is nearly the same as future use but perhaps slightly different).
Policy	Documents, strategies, Department of Health visions, future direction and plans (competing agendas). What current policy means for current ICT use.
Structural and Environmental	Availability of internet and cost of data, cost of cell phones and airtime, strength of signal. Information Governance e.g. confidentiality, security of data and privacy. Patient pathway description. Think in terms of individual/community and health system structures. Mobile coverage, landlines, roads, transport in rural areas (compared with urban) (Separate and fine code these later) landscape = policy+ structural+ environmental
Community	The ways in which mHealth will assist in improving a communities health. Community's needs. Community's resources.
Life situation	Coping with chronic illness / other illness Family/community support. Communication with Community health-workers/lay health-workers/home-based carers. You can have a code for everything that is mentioned about live situation for patients and for health professionals. What you will do with this is write summaries that capture the live experience of each participant (as you are doing with the clinics – you can also
Anything about the clinic	Code for 'anything about the clinic' to help with the clinic summaries)

	These summaries help with interpretation of data and to describe the research participants.
Positive experiences of healthcare	At clinic or hospital by nurse or doctor Healthcare seeking Healthcare reaching Healthcare utilization Healthcare needs Perception of needs and desire for care Financial accessibility Physical accessibility Quality of care Continuity of care Geographic accessibility Financial affordability Resource availability
Negative experiences of healthcare	At clinic or hospital by nurse or doctor (negative) Acceptability of services Experiences of staff

Appendix 9: Contextual results tables – further examples from Chapters 5 and 6

Table A. to describe the context and background of participant's lives and use of ICT by patients with chronic disease or pregnant women and health-workers

Context	Themes identified/ Organising macro themes and Examples
Life Situation	<p><i>Social protection grants</i> People expressed they were very reliant on their grants to buy staple food. “On my money for grant, I buy a big bag of mealie-meal (<i>ground maize flour</i>), and then the next month I will not buy it.” (<i>Patient 1, female, 50-59</i>) “I get a disabled grant for my chest and my heart failure but they sometimes cut the grant and I have to go to register again.” (<i>Patient 2, female, 50-59</i>)</p> <p>Employment/jobs “I am working on the side of the road in the project called ‘Siyatendela’; we are cleaning and cutting the grass...Department of those from road and transport.” (<i>Patient 3, female, 50-59</i>)</p> <p><i>Piece-meal work</i> “I am a fashion designer and I am sewing some comforters and sell them. I am sewing these clothes different kinds of clothes, school uniforms, traditions, weddings, decoration.” (<i>Community member 1, female</i>) “I am selling things at school (<i>to learners</i>); I was supposed to be there now (<i>but she was awaiting her clinic appointment</i>). I am selling sweets and snacks.” (<i>Patient 8, female, 60-69</i>) There are different social classes within the community and some people work as housekeepers for other families in their village. “I work as a domestic worker at some of the households.” (<i>Patient 9, female, 25-29</i>)</p>
Activities	<p><i>Chores</i> Particularly, chores such as collecting water and firewood are part of many participants' survival tasks.</p>

	<p>“I am going to cook, fetch water, do my laundry and going to fetch firewood.” (<i>Patient 2, female, 50-59</i>)</p> <p><i>Relaxing</i> - Some patients described what they do to relax</p> <p>“I just walk around my yard... After that I sit down and relax or have a nap.” (<i>Patient 1, female 50-59</i>)</p>
Pregnant at school	<p><i>School</i></p> <p>The women explained they are not taught about pregnancy in schools sufficiently, however this may be school-dependent.</p> <p>“They don’t teach pregnancy at school because we have a male teacher for Life Orientation courses.” (<i>Pregnant woman 7, 18-24</i>)</p>
Patient Diagnosis	<p><i>Chronic disease</i></p> <p>“When I got infected, I was working and saw one of my friends and she was sick; then I decide to go to the clinic and get tested so that I can know my status.” (<i>Patient, female 15, 30-39</i>)</p> <p>A patient explained she was attending the clinic but still not getting better so went to the hospital (not a referral)</p> <p>“I was coughing and losing weight and I didn’t understand because I don’t have a husband... they tested me and find that I am positive. (<i>Pregnant woman 17, 70-79</i>)</p> <p>Often patients attend the clinic for one condition and it is there they find out the have another problem.</p> <p>“I went there for family planning then the diagnosed me with high blood pressure and sugar diabetes.” (<i>Patient 19, female, 40-49</i>)</p>
Patient understanding of chronic illness	<p><i>How they currently feel now they are on treatment compared to when they were undiagnosed</i></p> <p>A recurring theme was that many patients complained of arthritis and lower-back pain in addition to their chronic illness. The chronic symptoms were being treated but the pain was currently present therefore often they were more interested in talking about the joint and bone pain because that is what they needed treatment for.</p> <p>“I have the aching bones that are bothering me.” (<i>Nkateko Patient 1, female, 50-59</i>)</p> <p><i>Treatment</i></p> <p>I am able to manage my condition because when I come to the clinic and given tablets I make sure that I follow what they are teaching us and use them correctly.” (<i>Patient 23, female, 50-59</i>)</p> <p><i>Diet and Exercise</i></p>

	<p>Many described how they changed their diet and lifestyle such as buying fruits and reducing salt and oil intake. “I do buy fruits and eat it, and also my food doesn’t have lot of salt.” (<i>Nkateko Patient 24, female, 60-69</i>) Patients referred to the educational talks where nurses had taught them about their lifestyle choices. “Here at the clinic they have taught us not to eat lot of salt and to take the treatment in time”. (<i>Nkateko Patient 1, female, 50-59</i>)</p> <p><i>Eyesight</i> Patients who need glasses to continue work also accessed private healthcare “I went there, when I wanted to take a public (driving) licence, when you are at the testing (driving test) you have to see everything there, that’s when they are giving you the licence. So my eyesight was not good. Paid R1900 for glasses” (<i>Patient 171, male, 60-69</i>)</p> <p>“They are not good; the left eye is sometimes having tears.” (<i>Patient 28, female, 50-59</i>) “Sometimes I see some blurred vision but they get well when I am fasting and praying they get well again.” (<i>Nkateko Patient 27, male, 60-69</i>) “I cannot see the screen...When things are written in in small letters I don’t see anything, I have to take it closer to my eyes so that I can read.” (<i>Patient 29, female, 30-39</i>) They are painful. When it’s hot and windy I can’t see anything. Like last week I was unable to see anything.” (<i>Pregnant woman 30, 18-24</i>) “My eyes are good but sometimes they are itching.” (<i>Pregnant woman 31, 18-24</i>) “I am able to see things that are nearer but things that are far away I cannot see it. I see some mist and clouds on my eyes.” (<i>Patient 32, female, 80-100</i>)</p> <p>Some patients’ bought second-hand non-prescription glasses from a market. Often these glasses were so old, the lenses needed replacing and their eyes, re-examined. Some said it was the medication they were on which caused the issues “I once told the nurses about my eyes that when I am coughing there are tears coming out and they have changed my treatment many times but nothing is changing.” (<i>Patient 32, female, 80-100</i>)</p>
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	<p>A doctor said explained that often it is the patients who are leaving it too late to access care for their eyesight often caused by diabetes. Once they do try to seek eye care the system attempts to assist them. She said it is actually only a minority who do try to access eye services even though many more actually need it.</p> <p>“They (<i>district hospital</i>) have got two optometrists and then they refer to X tertiary hospital, where they have got an ophthalmologist once a week.” (<i>Doctor 63, female</i>)</p>
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Table B. to describe the ICT use of patients with chronic disease and pregnant women, sources of patient education, hospital/clinic context and challenges

General organising theme	Themes identified/ Organising macro themes and Examples
Patient-Health Worker ICT Current Use	<p><i>Ability to use phone</i></p> <p>“What I am able to do is; when it rings I am able to press the green button and talk.” (<i>Patient 28, female, 50-59</i>)</p> <p>“Since we are old parents just phoning and receiving calls.”(<i>Nkateko Patient 6, male, 50-59</i>)</p> <p><i>Airtime</i></p> <p>“Most of the time I have airtime because if something happens, I am able to call.” (<i>Patient 29, female, 30-39</i>)</p> <p>For example a pregnant woman spends R5 per week and says ‘it’s just for ‘buzzing’ (SMS).” (<i>Pregnant woman 43, 30-39</i>)</p> <p>“I can say maybe a month without buying the airtime and people usually call me and receive call; I don’t have money to buy airtime.” (<i>Patient 16, female, 60-69</i>)</p> <p>Those with government paid jobs were complaining they have to use their own phone and airtime for work purposes, for example a social worker said</p> <p>“It’s not good because I can’t use my little money from the government.” (<i>Pregnant woman 49, 30-39</i>)</p> <p>People were on all three mobile networks although there was a distinct preference with Vodacom because of the R5 power hour deal allowing you to talk for one hour a day for just R5.</p> <p>“Sometimes I do buy airtime for R12 or I buy the Power Hour for R5.” (<i>Patient 50, female, 18-24</i>)</p> <p><i>Voice calls</i></p>

	<p>Often they would said the most recent examples of when they used their phone. Some explained they only use their phone when there is a problem such as to tell someone about a death of a family member.</p> <p>“I use my phone to call people and this phone has helped me a lot last year on December when my child passed away; I used it to call my relative and people from the mortuary.” (<i>Patient 16, female, 60-69</i>)</p> <p>Reasons for using the phone - business</p> <p>Some people have small businesses such as roadside stalls selling bananas, airtime and sweets. Some customers buy things on credit and they need chasing up over the phone when payments are due</p> <p>“I use my phone to call people who owe me money. Like when a person has taken soothing on credit and on month-end, I will call that person to ask her ‘when can I come to collect my money?’” (<i>Patient 53, female, 60-69</i>)</p> <p><i>SMS</i></p> <p>The majority of youth explained that they SMS regularly, especially to discuss health related matters.</p> <p>“When I had cramps, then I told my mom that I am having cramps... I will just send her an SMS and tell her how I feel.” (<i>Pregnant woman 54, 18-24</i>)</p> <p>“Like when I say ‘Come to my place today’, I will write = ‘<i>cm 2 m plc</i>’ or ‘How are you’ = <i>HW</i>’ and ‘school =<i>skl</i>’.” (<i>Pregnant woman 55, 18-24</i>)</p> <p>Another showed an example of a message on her phone “I write like this (showing us how she writes) like when I write ‘Where are you?’, I will write ‘<i>w a u</i>’.” (<i>Pregnant woman 54, 18-24</i>)</p> <p><i>Internet</i></p> <p>“Ah... searching for names that you don’t understand.” (<i>Patient 52, female, 40-49</i>)</p> <p>“I don’t know what it is because I never use it.” (<i>Patient 23, female, 50-59</i>)</p> <p>“I think it’s a social network just like to communicate with different people, to type some information on it, that’s what I am thinking.” (<i>Pregnant woman 43, 30-39</i>)</p> <p>“My children use it to chat with their friends. And I end up telling them that I don’t want them to chat because I don’t like it... Yes, I do see them when they use the Internet and chat but I do tell them not to do it because they end up not reading their books.” (<i>Patient 172, female, 60-69</i>)</p> <p><i>Social Media</i></p> <p>One participant described the amount of time she spends on social media</p>
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	<p>“Facebook... I think it’s once a week but WhatsApp you know it its WhatsApp.” (<i>Patient 11, female, 18-24</i>)</p> <p>This suggests that it is easy to be on WhatsApp all the time. WhatsApp messages ping through to the phone like a message whereas Facebook use is a more conscious decision and is more controlled viewing.</p> <p>When asked whether HIV patients talk with each other on social media about their status the majority said no they didn’t. Facebook in particular was viewed with caution and not enough privacy to discuss health matters. Facebook users are predominately using it on their cell phones as the sole device (unlike in many places where people switch between checking the Facebook app on their phone, tablet and laptop).</p> <p>Another person said using social media “makes people fight.” (<i>Pregnant woman 39, 30-39</i>)</p> <p>A pregnant women said he does not discuss pregnancy on WhatsApp with friends because “they talk a lot and gossip.” (<i>Pregnant woman 7, 18-24</i>)</p> <p>“By the time I was using WhatsApp, it was disturbing my education that is why I stop using it.” (<i>Pregnant woman 59, 18-24</i>)</p> <p><i>Photographs</i></p> <p>Infrequently people discussed sending MMS via social media apps or website</p> <p>“Like when I have shoot myself a photo (‘<i>selfie</i>’) then I send it to my husband or my friends” (<i>Pregnant woman 59, 18-24</i>)</p> <p><i>Computer</i></p> <p>“I don’t know how to use that technology but when I know it will be good”</p> <p>Doctor’s opinions of patient ICT use</p> <p>This was echoed by a doctor who said, a few of her patients, usually teachers, use the Internet</p> <p>“Very few, but we are having one or two teachers who come to consult who may do.” (<i>Doctor 62, female</i>)</p> <p>When asked what doctors thought patients used the Internet for their responses were similar whereby they do not think they are looking up health information and if so, only a minority do so but sometimes when they think it is possible they may encourage a patient to find out more about their condition using the Internet but this is on a case by case basis because abilities rarely so widely.</p> <p>“They are not looking up health information. I have not seen them do it, sometimes I say to them this is your condition, do you have access to Google and they say yes, but I probably do that with the younger patients, everybody has phones and access to one.” (<i>Doctor 63, female</i>)</p>
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Anything about clinic	<p><i>Nurses' work role</i></p> <p>“All the programmes, managing them all alone, it is really confusing.” (Nurse 68, female)</p> <p>There is a hierarchy of nurses, who start their day often with a meeting before or after prayers and signing with the patients and then the health talk.</p> <p>“Auxiliary nurse, then an enrolled nurse, is also called a staff nurse. Then there is a professional nurse.” (Nurse 92, female)</p> <p>She thinks teamwork is one of the most important things for the clinic to function well</p> <p>“As long as we work as a team and we communicate with each other there is nothing that can be hard.” A13 (Nurse 92, female)</p> <p>Patient capacity and staff shortage</p> <p>“Even the lay counsellors they help us a lot they retrieve files then those who come after – everyone in consulting room and nurse doing vital signs. They are here everyday. They don't have a special place.” (Nurse 77, female)</p> <p>“The problem is there are lots of patients and you find that you are alone on the minor and you have to see and after you have seen 40 to 50 and then your mind is no longer working properly you are tired.” (Nurse 75, female)</p> <p>“We have a shortage, we are short staffed. We delegate according to programmes.”</p> <p>“Shortage of staff - if you look at the queue it will take very long to examine need a lot of time, others are now complaining. That is our challenge and the clinic is very small and then services are too many.” (Nurse 92, female)</p> <p>Another nurse explained it was a shortage of human resources.</p> <p>Patients are the problem</p> <p>Patients do not always arrive on their booked day</p> <p>“The problem is the clients... don't comply. They are supposed to come earlier. What suffers is the programme, we are supposed to pre-pack (drugs) for the next day. The way we have planned is not working. Then the packing is only done in the morning.” (Nurse 80, female)</p> <p>She suggests that the “The clients are the problem”¹⁵ for the advised system not working properly.</p>

	<p>There is particularly a lot of writing to do in the maternity record books. “Of course, especially in the labour ward, we are writing a lot.... It’s the policy.” (<i>Nurse 76, female</i>)</p> <p>Nurse administration/paper work One nurse suggests that using a computer would make her work quicker “Ok, I am just thinking it may be quicker using a computer if you were trained maybe quicker if it was inputted into a computer.” (<i>Nurse 81, female</i>)</p> <p>One of the government policy-makers described primary care as “The heart beat of the South African health system and is not a cheap service.” (<i>National policy-maker 82</i>)</p> <p>Clinic environment <i>Queuing</i> - The nurses express exclamation at the time that patients arrive in the morning when the clinic only opens for its services at 7am every day “First come first serve. Ehhhhh! 5am! They want to come be the first number so they can be serviced first.” (<i>Nurse 95, female</i>)</p> <p>The patient summarises her day at the clinic “When I arrive here we queue and after some time the nurse told us to go and urinate so that they can test the urine, after that we go back to the queue. On my first appointment last month, they have tested me for HIV, after that we go to the consulting room and they check if the baby is fine. After that you are done for that day.” (<i>Pregnant woman 60, 30-39</i>)</p> <p>“When I am in the room with the nurse she will tell me about the results of the vital signs, if my blood pressure is high or middle or normal she will explain to me. And even the sugar level she will tell me the results.” (<i>Patient 83, male, 70-79</i>)</p> <p>“We are also human beings, we have family responsibilities, we are off sick, we are to go for annual leave. If one of us is in a meeting, there are only two, over covering that is there, you are not focusing one thing. ANC booking or Initiation of ART can’t be less than 30-45 minutes for each person, only one you get it very tough.” (<i>Nurse 68, female</i>)</p> <p><i>Clinic shopping</i> The concept of clinic shopping is not a new phenomenon. A few patients described why there were not attending their nearest village clinic and the reasons for switching clinics. A nurse said that often patients with HIV/AIDS do not want other people to know their status and they think by travelling further nobody will find out</p>
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	<p>“Patients are staying far but they choose to come to X clinic. Sometimes they default and say they did not have money to come to the clinic. They leave and come to this clinic.” (<i>Nurse 69, female</i>)</p> <p>This causes challenges for the nurses because it unnecessarily increases patient numbers. Chronic patients who do not want to be seen collecting treatment in their local clinic travel 20km to another clinics to not be seen.</p> <p>“I like this clinic and from where I’m staying, people are talking a lot and I want to keep my illness as a secret.”(<i>Patient 85, female, 30-39</i>)</p> <p>Another reason given by patients for changing clinics is the poor service and staff attitude they are receiving, long waiting times and sometimes without treatment.</p> <p>“At clinic X they are not treating us very well, you can come early in the morning and it goes to sunset and you went home without your treatment.” (<i>Patient 86, female, 60-69</i>)</p> <p>This suggest that patients are willing to travel further and spend more money to get better service</p> <p>“I don’t like the health centre because they are not treating us good.” (<i>Patient 14, female, 25-29</i>)</p> <p>Sometimes it was incomprehensible why a patient changed clinics, other than they are treated well.</p> <p>“When I come here they treated me very well, when they give me the return date they do give me the treatment when I arrive at the clinic. Even when my children are sick at home I am taking them to this clinic.” (<i>Patient 17, female, 70-79</i>)</p> <p>Another reason for delayed uptake of care is the person has had a dissatisfactory experience at their local clinic or has heard rumours of the perceived poor care given.</p> <p>This can lead to ‘clinic shopping’ where patients are wiling to travel further to another village’s clinic to get what they perceive is better care. This seemed to be a reoccurring theme amongst patients.</p> <p>“At clinic X they are not treating us very well, you can come early in the morning and it goes to sunset and you went home without your treatment.” (<i>Patient 173, female, 30-39</i>)</p> <p>It is difficult to establish how digital technologies could change this unless clinic services improve through the use of e/mHealth and therefore retain patients.</p> <p><i>Antenatal care</i></p> <p>“When you test for HIV, they prick you on the finger at the outside house in the clinic, and then you come to the consultation room, where they will collect blood on the arm and they measure your weight. After that they will ask history of your family, like is there anyone at your family, who is sick, smoking or drinking alcohol.” (<i>Pregnant woman 51, 18-24</i>)</p>
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	<p>even here at the clinic they are trying to motivate us to test two times, before giving birth and people refuse to test. You find that they do ask us to test but we refuse, even when they teach us the good and bad that will happen to the child, if we don't know our status and we have to test when we are eight months pregnant, but you find that a person refuse to test again."</p> <p>The nurses said that women now understand why they should deliver the baby at the hospital rather than the clinic because of the resources such as doctors. Women are becoming more educated about where it is safe to give birth.</p> <p>"Most of the patients we educate them, we tell them if they have problem or problems arise, must go to the hospital." (<i>Nurse 87, female</i>)</p> <p>At the same time the clinic has the facilities if necessary.</p> <p>"If a lady came in and she was in labour you could deliver obviously." (<i>Nurse 142, female</i>)</p> <p>However another nurse said</p> <p>"The facility is too small, we don't have enough equipment." (<i>Nurse 87, female</i>)</p> <p>The majority of pregnant women explained they were going to deliver their baby at the nearest district hospital. However some mothers, especially with their second pregnancy, preferred to deliver their baby at their village clinic but the nurses expressed resistance to that because the clinic is only opening for eight hours during the day. Therefore the expectant mother must have another plan if she is to go into labour when the clinic is closed.</p> <p>"Here it a eight-hour clinic, so you find that the community it serve they believe that we can also undertake some delivery of babies and it's difficult for us because we knock off at four o'clock, but we normally tell them that we don't deliver, they supposed to go to the health centre or the hospital, but some will just come then there is nothing you can do just have to deliver." (<i>Nurse 88, female</i>)</p> <p>The nurses explained that another reason is the lack of water supply in the clinic and it becomes difficult for the linen to be washed. On observation, there was no running water from the taps, by each sink; a reused Coca-Cola bottle was filled with water from the outside storage tank supplied by a borehole, for nurses to wash their hands. There are toilets inside of the building but they are not used because of the water shortage, so a long drop outside is the alternative.</p> <p><i>Education during consultation</i></p> <p>"They don't like asking questions maybe because they are always in a hurry. They don't like to sit for a long time. They become bored."</p> <p>Patients need to leave because they have things to do.</p>
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	<p>“To plough fields, take care of little ones, teenage pregnancies, remain with grandchild, mothers are going to school.” (Nurse 68, female)</p> <p><i>Education for pregnancy</i></p> <p>“They are teaching me that as I am pregnant, I have to stay happy all the time, I mustn’t get angry because it will affect the child.” (Pregnant woman 13, 18-24)</p> <p>Some pregnant women recounted what advice they had learnt from the nurses.</p> <p>“They told us that if you are pregnant and your headaches in the forehead you have to run to the hospital.” (Pregnant woman 56, 25-29)</p> <p>Nurses sometimes give pregnant women a sheet to fill out with how many times the baby kicks.</p> <p>“It teaches us how to behave when you are pregnant and you have to eat healthy food and how to protect yourself.” (Pregnant woman 7, 18-24)</p> <p>“I have learned here at the clinic because they normally teach us how to take care of your pregnancy and also from other moms at home; they do come and teach you how to take care of your pregnancy.” (Pregnant woman 38, 18-24)</p> <p>“They are teaching us lot of things like how can we use the treatment, and how to live with any chronic that we have and something like that. (Patient 84, male, 40-49)</p> <p>Pregnant women then ask the nurses questions as follows</p> <p>“I have ask them how many times that we have to test HIV/AIDS when you are pregnant and what must you eat most of the time.” (Pregnant woman 58, 25-29)</p> <p>“Like when I don’t understand the tablets that they have given me, I will ask why did they change my treatment and maybe it’s the cover of the box.” (Patient 15, female, 30-39)</p> <p>“Every month they do teach us. Things like when you want to have sex you must use condoms, teaching us about STDs and lot of things.” (Pregnant woman 47, 18-24)</p> <p>Some patients do not have time and want to go home rather than listen to the talk and ask questions “we are in a hurry sister.” (Nurse 96, female)</p> <p>Sometimes the patients give valid reason why they can not attend the health talks. She arrives late and misses the nurses lessons because</p>
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	<p>“Because of the transport. Sometimes you find that I left home at six (<i>am</i>) but the transport comes late until I arrive here at eight (<i>am</i>).” (<i>Pregnant woman 60, 30-39</i>)</p> <p><i>Health talks</i></p> <p>The patients explain they are taught about how they are meant to take their medication and keep clean.</p> <p>“Here at the clinic they told us that when you are taking treatment you have to eat first because if you take treatment without food they will not work well but when you have taken food the treatment will work well in your body.”</p> <p>“They were teaching us about how to bath.” (<i>Nkateko Patient 97, female, 80-100</i>)</p> <p><i>Doctors</i></p> <p>Another doctor said he tried to educate patients about changing their lifestyle to alleviate their health such as discussing diet and exercise. He says many of his clients have chronic conditions and are overweight because of their poor high-refined sugar diet.</p> <p>The issue of foreign doctors or at least South African doctors, only English speaking doctors needing a nurse to do translations during patient consultation. There is the issue of translation for example many of the doctors are not local and cannot speak the language, therefore a translator is necessary</p> <p>“I can probably get by with 59-60% of patients and with the rest I ask a nurse, student clinical associate sometimes if the patient comes with a relative and they are happy with the relative as an interpreter.” (<i>Doctor 70, male</i>)</p> <p>“They do have things on the radio – the DOH has a slot in the local Mpumalanga radio station called ‘Radio BBR’ (<i>Bushbuckridge</i>) and do a health talk every 2-weeks. So it is whatever would be in the media” (<i>Doctor 62, female</i>)</p> <p>Knowledge empowers patients to understand more about their conditions.</p> <p>“I want to have more knowledge, let’s say I have the signs of TB; I will know it and I have to test for TB.” (<i>Patient 14, female, 25-29</i>)</p> <p><i>Campaigns</i></p> <p>The nurses’ suggested that there are annual health campaigns</p> <p>“Sometimes we do have yearly campaigns.” (<i>Nurse 142, female</i>)</p> <p><i>CHW</i></p> <p>One patient explained that “most people don’t understand HIV and AIDS” and they need CHW to explain it to them face to face.</p>
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	<p>“They will help me to have more knowledge and I will also teach my children about it until they know and understand about HIV.” (<i>Patient 85, female, 30-39</i>)</p> <p>Some patients explained they could be weary of why the CHW is there and what they have to say, but then they realise the importance their visit to her family</p> <p>“They were not there for me but they come to see my husband because he is HIV positive. They were asking him some question then I decided to stay and listen to what they are saying.” (<i>Patient 173, female, 30-39</i>)</p> <p>Some patients said instead of home-based carers coming to their house they get their health information from the mobile clinics that attend a visiting point within their village (this is in addition to their clinic appointment). It was through this learning opportunity that she then knew when she should go to the clinic.</p> <p>“They don’t come to my house but on Wednesday we are going to the visiting point and we were learning there.” (<i>Patient 8, female, 60-69</i>)</p> <p>The doctor said described how the system is supposed to work</p> <p>“They are the first point of contact for those households, so the idea is that they will do immunisation, health advice when it comes to screening, diet and what they can’t manage they will then send to the clinic and then what they can’t manage they will send to the hospital. So there is a pyramid structure” (<i>Doctor 70, male</i>)</p> <p><i>No experience/contact of CHW</i></p> <p>Often patients said they had never seen a home-based carer at their home but they would like help</p> <p>“I never seen them, I have ask them two months back on November; I wanted them to come and see where we are staying so that we can get help there and there.” (<i>Nurse 50, female, 18-24</i>)</p> <p>She would like a community worker to come to her house and discuss pregnancy, which is better face to face than over a phone.</p> <p>“It will be good because I will not be shy when talking to the phone because I don’t see him.” (<i>Pregnant woman 47, 18-24</i>)</p> <p>Stigma associated with HIV and not wanting anyone to know their status is still very raw – didn’t want home based carers to visit because people can then gossip.</p> <p>The CHW are also responsible for Direct Observed Treatment of TB medication. However one nurse said it was not practical to expect each TB patient to be observed every time they took their medication over a six-month period.</p> <p><i>Family</i></p>
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	<p>“I think I have it but not that much (<i>understanding of chronic illness</i>), I will keep on asking to elder people to tell me, those who have lot of experience about pregnancy. My friends are telling me things about pregnancy but when I ask older people about it they don’t tell me what my friends are saying. I don’t know what to believe but some of the things I will believe it when I have my own child.” (<i>Pregnant woman 13, 18-24</i>)</p> <p>Asking a family members (<i>her aunt</i>) pregnancy related questions could help advise her</p> <p>“Like I will ask her if it’s good to get pregnant now and she said yes, if you feel like you are healthy that you can do it; then you can get pregnant and there is nothing that can stop you. And she always advise me to eat healthy, exercise and no stress but I don’t exercise because I am lazy and always in the car.” (<i>Pregnant woman 43, 30-39</i>)</p> <p><i>Peers</i></p> <p>The more that one person can be educated and spread the information they have learnt from mHealth initiatives the better. Some patients explained they discuss being on the same chronic medication</p> <p>“We do talk about it, like are you using this tablet, I am using it too.” (<i>Patient 21, female, 60-69</i>)</p> <p><i>Research projects</i></p> <p>A small number of patients described previously being in a university or government-led research project. This was not unusual being a study site as there are other health-related research projects happening and therefore some patients gathered health knowledge from the projects they or family members had been involved in. One patient with epilepsy said she only started accessing health services through a university intervention on epilepsy conducted by Wits and that is where she was diagnosed and learnt about her health condition.</p> <p><i>Newspapers and magazines</i></p> <p>“There are lot of things that we don’t know but through reading we become aware of some of the diseases.” (<i>Patient 154, male, 30-39</i>)</p> <p>“At home there was a lady next door and she was sick and when I come across those articles about HIV, it makes me become interested in reading it so that I can have more knowledge about HIV; and I will able to help other people when I have information.” (<i>Patient 57, female, 30-39</i>)</p> <p><i>Radio</i></p> <p>“There are lot of things that they are teaching on the radio; things like how to feed the baby. And what kind of lunch box does the child have to carry.” (<i>Pregnant woman 35, 30-39</i>)</p>
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	<p><i>TV</i></p> <p>Patients describe the feelings of reassurance and that when a TV programme discusses something they do not know, it will help them.</p> <p>“I do enjoy it because I am learning from it. There are things that maybe I don’t know and when it’s on TV talking about it I will know that if this happen I have to do this.” (<i>Patient 85, female, 30-39</i>)</p> <p>Many of the patients described exactly what they had learnt in great detail suggesting that when they learn something on the TV or radio they do retain it.</p> <p>Often patients call their friends who they think may be interested and tell them to watch the programmes, an informal knowledge sharing takes place</p> <p>“Somebody called me and said go and watch this on the TV because on Sunday I go to church.” (<i>Pregnant woman 54, 18-24</i>)</p> <p><i>Posters</i></p> <p>A patient explained why she thinks the information in the pamphlets is useful</p> <p>“I am reading them because nowadays there are lot of illnesses and I want to get more information.” (<i>Pregnant woman 40, 18-24</i>)</p>
Alternative care	<p><i>Payment</i></p> <p>A minority of patients explained that they family has medical aid which covered the doctor’s fee, this was rare but interesting that some families have health insurance</p> <p>“My children are taking me to the doctor using their medical aid.” (<i>Pregnant woman 39, 30-39</i>)</p> <p>The doctor’s explained that patients who use medical-aid were usually government employees in the police force, nursing, teachers and all other patients were cash patients.</p> <p>One private doctor explained that older patients receiving the pension social grant use that money to pay for the private consultation because they complain about the public facilities.</p> <p>One patient explained the first consultation is more money and then it is cheaper on the second return</p>

	<p>The average payment for a private doctor is between R250 and R350 according to the patients. This is similar to the amounts that the private doctors interviewed said they charged.</p> <p>Although some patients decide to use private doctors, one doctor said they actually trust the nurses at the clinic more than the private doctors (she was unable to give the context of why she felt the doctor was not telling the truth).</p> <p>“When come here they are telling me different things, then I realise that the doctors is not telling me the truth.” (<i>Patient, female 14, 25-29</i>)</p> <p>Often, patients are referred back to the clinic, by the private doctor because they know the patient needs higher level care. If they are not content with the care they received at the clinic and the reason why they went to see a doctor, they sometimes switch clinics for better perceived care.</p> <p><i>Health professionals view on healers</i></p> <p>A doctor told us that many of his patients describe experiences of going to see healers and are that people are taking traditional and western medicine.</p> <p>“A lot of people get health advice, they will go by what they have heard and experience a lot of believe in witchcraft. I have met people who have had operations and snakes removed from their stomach, they genuinely believe I had a snake cut out of me. Very often people are taking both or they will try traditional and then try ours and then neither will work probably.” (<i>Doctor 146, male</i>)</p> <p>The nurses said that the patients “are using herbal medicine. Some do tell us, other does not tell us even if they use them.” (<i>Nurse 76, female</i>)</p> <p>On of the optometrist believes that some traditional healers can damage the patient’s eyes when they are trying to heal them for poor eyesight.</p> <p>“I don’t how to call it when they go the healer whatever they present with the healer takes them into the boiling water and they put blankets over they tell the person to open eyes... yes vapour comes into their eyes, they put some medicine into the water, I don’t know what medication, that medicine when it mixes with hot water steam has a certain mixes and come to the eyes, so you found that vapour forms chemical, then chemical comes into the eye a big problem.” (<i>Government Optometrist 26, female</i>)</p> <p>Those seeking eye care from traditional healers before coming through the public health service are in fact sometimes doing more damage to their eyes as this example illustrates.</p>
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	<p>Payment to healers</p> <p>Some patients explained that the cost of going to a healer is too much money, so although they believe in it they can not afford it.</p> <p>“No I don’t go there because they are expensive.” (<i>Nkateko Patient 161, male, 60-69</i>)</p> <p>Sometimes patients felt the healer was not healing them and so they felt like they were wasting their money.</p> <p>“I used to go in the past but I didn’t get cure, then I realise that I am wasting my money. I went to the traditional healer at Village X and I didn’t get cured, then I decided to come to the clinic.”</p> <p>Healers are not always paid in money but whatever the patient can give at that time, be it their time, clothing or an animal.</p> <p>“The forms of payment you can pay in cash or else you say no I don’t have cash lots of people are not employed someone can say, I will give you a chicken.” (<i>Nkateko Patient 1, female, 50-59</i>)</p>
Health Worker- Health Worker ICT Current Use	<p>Doctors phone use for work</p> <p>However, another doctor explained that the health facilities lines can be easily stolen</p> <p>“Used to have problems with their phone lines being stolen but now have satellite phones, which are reliable and seem to always work.” (<i>Doctor 62, female</i>)</p> <p>Airtime for health-workers</p> <p>The purchasing of airtime is not always possible</p> <p>“Sometimes I do stay for a long time without airtime, if I don’t have money to buy it.” (<i>Patient 41, female, 50-59</i>)</p> <p><i>Email</i></p> <p>“When you are speaking to people and they are in a rush then they can’t take the full story but if you sent it to them, then they can.” (<i>Doctor 125, male</i>)</p> <p>However this process only works because she uses her personal email provider and relies on the knowledge of the specialists’ personal email address and their willingness to work in this casual way.</p> <p>“When I have had a difficult patient that sometimes I want to transfer and I know the email address of the psychiatrist in Town X.” (<i>Doctor 62, female</i>)</p>

Anything about hospital	<p><i>Undifferentiated patient</i> (Patient presenting late)</p> <p>We asked the doctors the reasons why patients said they had not sought medical help before</p> <p>“Some of them they will tell you, they did not know they could get help at the hospital, they didn’t have money, to come to the hospital, they don’t have anyone who is taking care of them.” (<i>Government Optometrist 26, female</i>)</p> <p>The doctor described who his patients were in terms of nationality and employment</p> <p>“There definitely are patients who are not South African but who have been here for a while, Zimbabweans and Mozambicans. Many are from the rural villages and the rural townships and some are from farms, driving vehicles or sorting fruits.” (<i>Doctor 89, male</i>)</p>
Healthcare Challenges	<p><i>Lack of specialist</i></p> <p>“The referral system to get things like ultrasound in a tertiary hospital. It is improving but still a lack of specialists. So here in this hospital at the moment, I am a family practitioner, but there is no medical specialist. We have one orthopaedic specialist and everyone else is actually quite young.” (<i>Doctor 63, female</i>)</p> <p><i>Infrastructure</i></p> <p>“We have enough staff but we do not have enough space.” (<i>Nurse 87, female</i>)</p> <p><i>Blood</i></p> <p>As discussed the lack of emergency blood supplies is further hampered by the inability to transport it to the hospital.</p> <p>“It is very expensive to set up blood transfusion and by allowing few stock of blood to be kept by hospitals, the non-emergency blood are processed at a central point. It is also excellent for quality control.” (<i>Provincial policy-maker 101, male</i>)</p> <p>The doctor explained the blood is kept for “obstetrics and all trauma that comes in and if you want to use it for some granny on the ward who has been tolerating low haemoglobin for a long time then you don’t. Get her to wait and order it from the clinic.” (<i>Doctor 67, male</i>)</p> <p>Another doctor commented that</p> <p>“I think that it is blood is generally in short supply and they probably can’t afford to give more emergency blood.” (<i>Doctor 89, male</i>)</p> <p><i>Hospital capacity</i></p>

	<p>The orthopaedic surgeon gave countless examples of where he had patients with broken bones through transport accidents or falls for example, taking up beds at the district hospital because they are waiting to be referred to the tertiary hospital. The wait can be so many months that eventually he has to speak to the family and see if the patient can go home untreated because the hospital does not have the services to help them or the capacity to keep them.</p> <p>Another doctor gave his account of the same women with bone fracture</p> <p>“We decided that they may as well go home that the operation was unlikely to happen for them and eventually they become pain free.” (<i>Doctor 89, male</i>)</p> <p>The doctor gave an example where patients often die prematurely because they are unable to have certain procedures because machines were broken and then be referred.</p> <p>“Sometimes people would do a bit better if we could get them to a higher care bed but there is just not higher care beds available.” (<i>Doctor 146, male</i>)</p>
Positive Experiences	<p>Many of the interviews focussed on the positives aspects off the system too. This was perhaps the doctors had not had many opportunities to vent their frustrations and complaints to an outsider before. The interview gave them time to reflect on what they felt were their everyday challenges, if any. So therefore the amount of discussion was more about the negative aspects of the health system. However some positive attitude were reflected and we have documented these</p> <p>“I must say I am impressed with what they are doing for HIV.” (<i>Doctor 128, male</i>)</p> <p>One doctor said that how the government has stepped up the fight against HIV is impressive and that they must take pride in small achievements</p> <p>“The roll out of anti-retroviral treatment in South Africa down to the level of nurses in the clinics initiating treatment proves that things can be improved where there is will and NGO/government partnerships.” (<i>E/mHealth expert 36, female</i>)</p> <p>Empathy and comradery of rural doctors</p> <p>“I feel like my passion is definitively directed towards rural health. Living in city is really cool, but my heart is definitively is in the rural areas, my heart breaks for them (the patients), I don’t think I would leave that.”</p> <p>The clinical associate students were very positive about their course because of the benefit of their job role in the rural areas.</p>

Appendix 10 : Interview schedules for each participant group

Phase 2a) Vutivi Chronic Disease Patients

Please can you tell me your name, village which you are from and how many children you have?

How did you arrive at the clinic?

Who did you come with to the clinic?

What time did you arrive at the clinic?

What do you do whilst you are sitting in the queue?

What activities do you do during the day?

How do you earn money?

Do you receive government social grant? Which one?

Questions about the chronic condition

Can you tell me why you are here at the clinic today?

Are you suffering from more than one condition?

Can you tell me about your condition?

When were you diagnosed with your condition?

How often do you come to the clinic?

Do you always come on the right day?

What happens when you get to the clinic?

What happens when you see the nurse?

What happens when you are collecting your medication?

What happened the last time?

How long do the consultations take?

How long do the consultations take?

Tell me about the time you saw a doctor about your condition?

Have you ever seen a private doctor?

Tell me about that.

Who who looks after you?

ICT Questions

CELL PHONES

Do you own a cell phone?

Can you show me your cell phone?

(Write down which make they have and a short description about it)

How many cell phones do you own?

What do you use your cell phone for?

Anything else?

Does anyone else use your cell phone?

Why is that?

Can you give me examples of when you use your phone during the day?

Can you tell me how you got your phone?
Which network are you on?
Why?

Are there times that you don't have airtime?

When/why?

Do you buy your own airtime?
Where do you buy your airtime?
How much do you spend on airtime?
Can you tell me how often you buy airtime for your phone?
How do you decide how much you want to spend on buying airtime?
How long does that airtime last?

Why don't you send messages?

Do you have an email address?

*Can you show me an example SMS on your phone.
Do you use predictive text/text speech (abbreviated words).
What languages do you write the messages in?
Is your phone important to you?
Why is this?

What else do you use your phone for?

For chat.....Mxit, Whatsapp etc.)
Do you enjoy using it?
How did you learn to use it?
How did you hear about it?
What groups do you belong to?
Why don't you use it?

INTERNET

Tell me about your experience of using the Internet?
Please give me examples.

*Once they have explained examples, ask them if they will show you on my phone – do a Google search with them using the topic they have searched for on their phone in the past.

What do you search for/what do you look up?

Have you ever searched for health information on the Internet?

Have you heard about the numbers you can SMS for free on your cell phone to get health information about your condition?
Would you use it, if you could access these services? If so, why?
Is this something you would tell your friends and family about?
Why?
What type of things do you think *The free health messages to your phone* would be good for?
What sort of people/age group/health condition?
Have you ever visited an Internet café?
Can you tell me a bit about it?
Where is the nearest one to where you live?

How much did it cost? Was it popular there?
Why have you not ever visited an Internet café?
What do you think the Internet is?
Why have you never been on the Internet?
Do you know of any family members or friends who use or have used the Internet?
Do you know what they use it for?
Please give me an example.
Have you ever asked them to look up something for you on the Internet?
If so, can you tell me about it?
What did you ask them to search for?
Why did you ask them to search this information?
Do you think that if you had access to the Internet, you would use it?
What do you think you would use it for?
What do you think Google is?

COMPUTERS

Have you ever used a computer?
What did you use it for?
Who taught you?
Does anyone in your family use a computer?
How good is the Internet speed?
Do you ever watch health programmes on the TV or listen to it on the radio?
Can you describe them?
Have you ever then gone and looked up more information about the health topics they were discussing on their website or phones the free number at the end?
Why/Why not?
Was it useful?

Health education

Can you tell me about the time that you were told you were diagnosed?
How did you learn more about your condition?
Can you tell me about the health education talks here at the clinic?
Are they useful?
Do you ever ask questions at the end?
Can you give me an example?
Can you tell me about the health posters around the clinic?
What do you think about them?

Where else do you find health information from?

Adherence

Tell me about how you remember to take your medication?
How?
Do you think it would be helpful in managing your condition if you were to receive a SMS reminder on your cell phone to remind you to take your tablets?
Why would this be a good thing?
Tell me about how you remember to attend your appointments?
If you received a SMS to your cell phone to remind you to come to your appointment the next day, do you think this would be helpful?

Why would this be helpful?
 Would you talk to a health professional over the phone about your condition?
 Have you ever used a tele-doctor (remote doctor)?
 Would you use one?
 Has a community health-worker or home-based ever visited your home?
 Please can you tell me about this experience?
 If not, why would you like one to visit?

Eyesight

How is your eyesight?
 Do you struggle to see your cell phone screen?
 Can you read the text on your phone?

Does someone help you use your phone?

How long have you had a phone?
 What problems do you experience with using your phone if your eyesight is poor?

Glasses: Where did you get your glasses? How they came about wearing glasses?
 Were you referred by the clinic to the hospital?
 How much was the eye care?
 Can you explain the process?
 Thank you for participating.

Phase 2b) Nkateko Patients

(Same as Vutivi). Additional questions presented below.

Intervention related questions

What did you do to remember to come to the clinic? (phone alarm?)
 How did the clinic remind you about your clinic appointment with the nurse today?
 (Options: SMS to cell phone/phone call to cell phone/visit from home-based carer if no cell phone in that household)
 Tell me about the SMS/phone call you received to your cell phone?
 Whose cell phone did the SMS get sent to/phone call come through too?
 What did the message say?
 How did you feel about the (SMS/phone call/visit in person) reminder?
 Why was the SMS/phone call/visit in person reminding you to come to the clinic helpful?
 Depending on which reminder they received:
 Is there some other method that you would find better? (they may have other ideas?)
 Would you prefer a home-based carer to have visited your house?
 Would you have preferred a phone call?
 Would you have preferred a SMS?
 Would you have preferred none of the above?
 Did you reply to the SMS/phone the number back?
 If so what did you say?

Why did you decide to reply?
Did you trust the person who wrote the SMS/called you?
Is this something you would like to receive every month? Why is that?
How do you feel about speaking to a nurse/doctor over the phone about your hypertension? Would you use that resource if it were available (I am thinking about HelloDoctor – whereby a patient can call a health professional if they need expert opinion about something).

Access questions

How do you get to healthcare?
How easy is it for you to get to the clinic?
What mode of transport do you use to arrive at the clinic?
Are you suing the clinic in your village or are you coming to another village clinic to be treated?
If the latter, why is this?
Have you ever been to a mobile health unit, which has come to the community?
How do you know when the mobile health unit is visiting?
Would you like it if you received a SMS to tell you they were coming?
How did you feel about that experience?
Have you ever visited another health professional about your hypertension?
(prompt: *traditional healer/private doctor/private-public partnership i.e. Bhubezi*)
How do you find getting hold of your medication?
Does the clinic always have your medication to give you? (*below are prompts*)
If not, tell me about the times when they don't have your medication?
Do you know why they didn't have your medication?
Have you ever bought your hypertensive medication from a private pharmacy?
If so, why did you do this?

Questions to ask Naketko Lay Health Workers

Please can you explain your job role?
What do you think about the appointment reminders?
Can you tell me about any times when the patients replied via SMS?
Can you tell me about any times when you phoned the patient to remind them and you had a conversation about you reminding them?
Have any of the patients talked to you about the SMS/phone call whilst you have been in the clinics?
Have any patients asked not to receive the SMS/phone call?

Phase 3) Pregnant women interviews and focus group discussions

(Same as Vutivi). Additional questions presented below.

Questions about the pregnancy

Can you tell me why you are here at the clinic today?

Are you suffering from any chronic conditions?
 Would you like to tell me about it?
 How often do you come to the clinic?
 Do you always come on the right day?
 What happens when you get to the clinic?
 What happens when you see the nurse?
 How long do the consultations take?
 How long do the consultations take?
 Tell me about the time you saw a doctor about your pregnancy?
 Have you ever seen a private doctor?
 Tell me about that.
 When did you start coming to your ANC bookings?
 Can you tell me about your ANC appointments?
 Where are you going to deliver your baby?
 Why?
 Where did you have it done?
 Were you shown the image on the screen?
 What did you think?
 Why did you have the scan (routine or complication)?
 If you have not had a scan, is this something you would like to have?
 Why?

Health education

Can you tell me about the time that you were told you were pregnant?
 How did you learn more about you were pregnant?
 Can you tell me about the health education talks here at the clinic?
 Are they useful?
 Do you ever ask questions at the end?
 Can you give me an example?
 Can you tell me about the health posters around the clinic?
 What do you think about them?
 Where else do you find health information from?
 Who do you talk to about your pregnancy?
 How knowledgeable are you about your pregnancy?

Phase 3b) Focus Group Discussions with pregnant women

Same as individual pregnant women questions. Additional questions presented below.

Are you willing to pay for mHealth cell phone services – getting health content message to your cell phone? Why/why not?

 Who would you like to teach you to use a mHealth applications (e.g. community health-workers/nurses/family?)

 Would you prefer to receive messages from the government Department of Health

or from private companies or your mobile operator? Why?

Have any of you heard of Momsconnect? *The government are going to register all pregnant women at the clinic and ask if you want to sign up to receive health message to your phone which include information on nutrition, how you are feeling and if you opt in: HIV related messages. It will be launched at the end of the month. The Minister talked about it in his speech this week.*

Would you like the service to be interactive? Two way? e.g. you can reply/write back?

Phase 4a) Nurses

Introductions

Please can you introduce yourself?

-Name, village, how long they have worked at this clinic, what type of nurse? How long have you been a nurse for?

Tell me about your use of ICT (computers and cell phones)?

What do you use your cell phone for?

(If relevant, what do you use your computer for? Email?)

Tell me about your experience of using the Internet? (Seek specific examples)

How good is the Internet speed? (If they have mentioned they have Internet at home) What is the cost of the data bundles/ WI-FI?

Do you have any apps on your phone? (If yes) Please tell me about them <may need to give an example of an app here since the word 'apps' is not commonly known?

For each of the above that is used – ask:

Do you enjoy using it?

How did you learn to use it?

Please describe the type of facilities and equipment that the clinic has?

Fax/landline/photocopier/computer/printer/modem/internet connection/digital camera/blood pressure equipment/ECG/d/blood tests apparatus

(After they have named the equipment....)

Who uses it? What for?

Who looks after it?

Is it working? (Prompt for reasons why it is/is not working?)

What is your job role at the clinic?

What are your daily tasks?

How much of your day is spent doing each task

E.g. paper work/vital signs/packing meds/writing clinic notes

Are there other tasks you do (not daily ones/from time to time)?

How long does each non-daily tasks take?

Do you use a cell phone, the Internet or a computer for any of your work tasks?

Which ones?

How do you use it/them?

Do you think cell phones, the Internet and computers could play a role in any of the tasks that you do at work in the future?

What would you say are the most challenging aspects of your job?

What is challenging about (each aspect that you mention?)

How could they be made less challenging?

What could be the future role for cell phones/ the Internet and computers to address some of these challenges (you face at work)?

Are there any problems the clinic experiences that you have not mentioned?

What could be the future role for cell phones/ the Internet and computers to address some of these problems (that the clinic faces)?

Are patients using their cell phones to access healthcare/health information? <The difference between accessing healthcare and accessing health information?>

Please give me some examples from your experiences

Is there a role for patients using cell phones to access healthcare in the future?

(What is another word for role? Function/position/place/value?)

(Rephrased)

Is there a role for the use of cell phones by patients in the future to access healthcare information?

Is the use of cell phones to access healthcare by patients something that could become possible in the future?

Why do you think this is?

Is there a role for the use of cell phones by patients in the future to access healthcare information in rural areas? (Still not content with how this is phrased?)

Have you heard about the numbers you can dial for free on your cell phone to get health information?

Do you tell your patients about this sort of thing?

What type of things do you think it <The free health messages to your phone> would be good for?

What sort of people/age group/health condition?

Conclusion

Do you have any questions they would like to ask?

Reminders:

Make sure they take away their participant information letter

Make sure I have stapled the audio consent to the normal informed consent.

Phase 4b) Doctors

Introduction

Describe your role as a rural doctor and what work you do here at this district hospital.

What is it like to work at the district hospital?

Have you worked in a rural Clinic? If so, please explain.

How long have you been working in the rural areas?

Have you worked in the private sector in SA or in another country before?

From your experience working in the NHS in the UK, can you see areas of e-Health in use there that could be applied within the public sector in rural South Africa?

When did you qualify?

During your student medical training, were you exposed to e/m-Health?

Main body of Questions

I want to explore the current use of digital and networked technologies in healthcare by doctors in rural South Africa.

Tell me about your use ICT at work?

Please can you give examples.

Did you or the DoH instigate this?

Please can you explain if you use a laptop/tablet/desktop and cell phone what you use it for?

E.g. Checking blood tests online using an Internet enabled cell phone

Please give an example of when you have used e/m-Health in your consultations?

What was this specifically for?

Have you ever used an m-Health tool as a “Decision Support Tool”?

If so, can you explain to me what was the context?

Are there any areas of ICT, which are not in use even though the equipment and the functionality to do so is in place?

Probe: Nurse’s use of computers

What was the patient’s reaction when you use these in the consultation?

Do you use any health apps during your consultations?

Please give an example?

Do you think e-Health could play role in drug stocks? In what way?

What are your views on patient electronic records?

Can you describe an aspect of your job, which is time-consuming?

Probe: paper work

Questions regarding m-Health and Patient use:

Are you aware of any of your patients using their phones to help manage their condition?

Can you give me an example of where patient and doctor interaction could benefit from using m-Health?

Have you had experience of talking to your patients about certain m-health applications?

Can you give an example of a patient using m-health?

Are there certain diseases/conditions you feel would benefit from the use of m-health in particular?

Opinions Questions

What are some of the challenges of your job?

What are some of the needs of the clinics?

Describe what you think could be some of the limitations and barriers of e-Health. Please give examples.

Probe: Policy/Structural/Environmental/Social/Economic/Human Resources

What are some of the factors that could influence the uptake of e-Health in South Africa?

Can you describe any potential future digital and networked technologies that you feel would enhance healthcare and be useful in these rural areas?

What does the Department of Health need to do to make e-Health successful within the health system in South Africa?
What is your projection for the future of m-health in rural South Africa? I am thinking about use by health professionals and use by patients.

Phase 5) Health worker additional e.g. Optometrists

Can you tell me what you do and describe in detail the tasks that you carry out?
Where did you train?
Please tell me more about what it is like working as an optometrists in this district hospital?
Where else have you worked?
How many optometrist work in the hospital?
Do you have the equipment you need?
How often do you work?
Can you tell me about the outreach programme? (where do you go? Which villages? How do you get there, who do you treat? How do they know you are coming? What services do you provide?
How do referrals work?
What does your job entail?
Do you cover eye health care?
How many of your patients are diabetic?
Do you have to refer many patients to further eye specialist?
Are you aware of any of your patients who had glasses made abroad the health train?
Where are the lenses for the glasses made?
How do the patients get to see you? Are they referred from the primary health clinic and or the hospital doctor?
How much is paid for glasses?
Who are the majority of your patients? Can you describe them?
Do you think many of the older ladies or men can read their cell phone screens?
What technology do you use?
Do you have a cell phone?
What do you use it for?
Do you ever communicate with your patients via your cell phone? (if so how and what for?)
Why do some people have poor eye health?
Are you dealing with large number so of people who struggle with eye sight?
Do many patients see a private optometrist?
How much does that cost (for a private consultation)?
Does that include a new pair of glasses?
Do many members of the community wear sunglasses?
Do many people have contact lenses?
How much is the cheapest pair of bifocals?
Can you explain some of the eye problems that people come to you with?
How do you think these people acquire these problems?

What kind of people comes to you for eye care? Please describe certain individuals?

What is the referral system like from the clinic to the hospital?

What would you say are some of the main causes of poor eye sight? (apart from old age?)

Do people look after their eyes?

Are people taught about eye health? Are there public health campaigns?

Do any of your patients ever complain that they can not see their cell phones screens therefore read the text or see who is ringing?

Are you seeing many blind people? Partially blind people? What are the causes for that?

Vision

Are many of the patients you see coming to you too late? (or at least later than should have first come to see someone about their eyes?)

How is child eye dealt with? Do school nurses do this?

Phase 5b) Clinical associate students

What is your name and where are you from in South Africa?

Describe your role as a Clinical associate student and what work you do here at this district hospital.

What made you want to become a Clinical Associate?

What is it like to work at the district hospital?

Have you worked in a rural clinic?

If so, please explain.

How long have you been working in the rural areas?

Main body of Questions

I want to understand your current personal and work use of digital and networked technologies in healthcare by clinical Associates in rural South Africa.

Tell me about your use ICT at home - personal?

Please can you give examples.

Tell me about your use ICT at work?

Please can you give examples.

Were you told why you were given a tablet by the university? What are you meant to use it for?

Can you tell me about your use of digital devices before becoming a student?

Internet use etc./Smart phone

Can you tell me about your use of digital devices after becoming a student?

How would you describe your ICT ability?

Are you an avid user of technology? Would you say it helps with your students?

And your role as a Clinical Associate?

Why do you think technology helps your every day work/learning

What would you say are the most important features/aspects of using your tablet?

How much data (airtime) are you supplied with?

Is this enough data?

Do you buy more data than you are given with your personal money?

What sort of website for e-Learning do you look up?
 Does the group of a clinical associate students help teach each other when it comes to digital devices such as cell phones and tablets.
 Please can you explain if you use a laptop/tablet/desktop and cell phone what you use it for?
 E.g. Checking blood tests online using an Internet enabled cell phone
 Do you use any health apps during your consultations?
 Please give an example?
 Have you heard of the concept of eHealth and mHealth?
 If so what do you think it means?
 Do you think e-Health could play role in drug stocks? In what way?
 What are your views on patient electronic records?
 Can you describe an aspect of your job, which is time-consuming?
 Probe: paper work
 Are the doctors and nurses and even patients using digital devices in their work?
 Please give examples?

Questions regarding mHealth and Patient use:

Are you aware of any of your patients using their phones to help manage their condition?
 Can you give me an example of where patient and doctor interaction could benefit from using mHealth?
 Have you had experience of talking to your patients about certain m-health applications?
 Can you give an example of a patient using mHealth?
 Are there certain diseases/conditions you feel would benefit from the use of m-health in particular?
 What are some of the challenges of your job?
 What are some of the needs of the clinics?

Phase 6) Community members

Please can you tell me your name, which village you are from and how many children you have?
 I want to learn about your role in the community.
 How do you earn money?
 Describe this in detail (e.g. shop seller....what do you sell? Who buys from you?
 What do you spend your money/profit on?)
 Do you receive government social grant? Which one?
 Tell me about your village and community.
 (places, things, events, people)
 Describe some of the people that live here.
 Tell me about unemployment in this village?
 Why is this?
 When is the next pension day when everyone sells goods?

Cell phone use

Do you own a cell phone?

Can you show me your cell phone?

How many cell phones do you own?

What do you use your cell phone for?

Anything else?

Do you use your cell phone for work purposes? Give me an example.

Does anyone else use your cell phone?

Why is that?

Can you give me examples of when you use your phone during the day?

Can you tell me how you got your phone?

Which network are you on?

Why?

Are there times that you don't have airtime?

When/why?

Do you buy your own airtime?

Where can people buy airtime in this village?

How much do you spend on airtime?

Are you aware of any one having phone contracts?

Can you tell me how often you buy airtime for your phone?

How do you decide how much you want to spend on buying airtime?

How long does that airtime last?

Cell phone use in the community:

What are your customers using their phones for?

What are your family using their phones for?

Do any of your customers (Are there people in the community) not have a cell phone?

Who – examples?

Do people use social media on their phone?

Do you enjoy using it?

How did you learn to use it?

How did you hear about it?

What groups do you belong to?

Why don't you use it?

Internet Use

Tell me about your experience of using the Internet?

Please give me examples. What do you use it for?

Can you access the Internet on your phone?

What do you search for/what do you look up?

Do you have an email address?

Community access to Internet and mobile technology

Is there an Internet café in this village?

Who uses it? Where is it? What do they use it for?

What is your friends, family and customers (What do you think are the community) understanding of technology (ICT)?

What are some of the reasons why you think people would like to use the Internet?
What do you think are some of the key barriers to (community members) people you know not having access to the Internet?

Computer use

Have you ever used a computer?
Does any one in the community own a computer?
What did they use it for?
What would you say are some of the barriers to people learning how to use a computer?
Are you aware of children in your primary and high schools learning computer lessons?

Community needs

What do you think your community needs to become more advanced digitally?
Are you aware of people having and line phone/internet/Wi-Fi in their homes?
What other forms of infrastructure are needed here in this village to make progress?
What other resources does this community benefit from?

Health in the community

What are the general thoughts about the nearest clinic/health facility to you?
What are the nurses like?
What is the general health status of this community?
What do you think is the largest disease/biggest health problem in this community?
What are your thoughts on the government bringing in a free SMS services whereby all pregnant women in the community would receive SMS to their cell phones about theirs and the baby's health?
Why do you think is good or bad for the community?
Are most mothers and babies healthy in this community?

Health education/promotion

Are there public health campaigns educating the community about healthy lifestyle/disease prevention?
How and where?
Where does the community/people you know get health information from?
Does the community/ people you know discuss health related issues with one another?
Do people in the community use their phones to assist with their health?
How? Please give me an example.

Phase 7) Policy-makers

What is the nature of your job?
Are you a DOH employee?
How long have you been working in the position?
What were you doing prior to this?

Do you work on one project or many at once?
Were you involved in the recent m-Health task team?

Can you talk me through the NHIS – the national health information system and the role of this in the e-Health strategy?
DHIS – how does this fit in?
What is it used for?

Who analyses the stats? x told me about the m-health pilot – whereby CHWs are inputting household level data into cell phones which is sent to the NDHI – can you explain this.

Main body of Questions

What is happening now – in particular the e-Health Policy.

I want to discuss e/m-Health for primary care in rural South Africa – can you tell me more about the current e-Health policy environment.

One hears varying degrees of where the government's e-health strategy is at the moment – can you comment on this. (We will narrow into the m-health strategy further on).

In your opinion where would you say the e-Health policy is up to right now?
(There is little evidence of the policy in the rural areas).

Where is the government heading with this?

I see South Africa is using China's model of National Insurance, which includes the e-Health strategy because of its experimentation and evaluation approach?
Can you tell me more about this?

Can you tell me out of the government's expenditure on the nation's Health system budget, what proportion is being spent on the development of e/m-health?
(Is this publically available?)

What are some of the main policy issues in relation to the uptake or non-uptake of e-Health strategies?

Do experts in the e/m-Health field, when developing a strategy, advise the policy-makers?

How much interaction and overlap is there with academic research on this?

The e-Health strategy has said it will 'resolve the problems of the past' in the NSA 2010-2014, do you believe this is possible?

Programmes

Does the government work closely with NGOs and private companies?

What hold does the government have over programmes that are government led but NGO run/initiated? (I am referring to joint partnerships backed/commissioned by government)

How closely does the NDoH work with University and Foreign Donors (DFID, USAID?)

What influence have any of these stakeholders had in the development of the e-Health strategy or smaller related programmes?

Who in the NDOH is the driver on these types of projects? Who makes the decisions?

Do you learn from other sub-Saharan African governments in terms of successful healthcare interventions? Example.

mHealth

I believe that the NDoH have been reviewing Maternal, Newborn and Child Health (MNCH) related m-Health initiatives and are moving ahead with a pregnancy registry for all pregnant women who sign up, to receive MNCH related content.

Do you know anything about the MomConnect based on the MAMA application that is set to be rolled out soon?

If not, who in government does?

I have heard from an anonymous source that there was a delay in rolling out the MAMA (MomConnect application) for pregnant women, can you comment on why this delay occurred?

Will the programme be integrated into the existing healthcare structure/facilities in both rural and urban settings/communities?

How have you thought about programme sustainability? (Funding/government/community).

I have heard about the new Government m-Health strategy that has been sent out to experts for comment (although I have not had access to it myself)

Can you provide me with any more information about this?

Who could I ask to read a preliminary copy because I understand it is not in the public domain as yet?

Is this m-Health strategy part of the government's attempt to reduce maternal mortality following the MDG 2015 guidelines? What are your thoughts on this?

Have the government been in talks with the GMSA who analyse the data industry?

Are there negotiations with the tele-com providers taking place to finance the publically provided SMS?

Infrastructure

***The ICT Infrastructure:** access to electricity/geographic location/poverty rates/literacy rates/education/ethnicity/connectivity costs/local and relevant content/technical local social appropriation/sustainability/ICT capacity building/ICT capabilities/information literacy/communication capabilities/content capabilities.*

Do you think South Africa has the necessary infrastructure to support e-health?

What would you say are some of the enablers to e-Health in SA?

What would you say are some of the barriers to e-Health in SA?

What are the impediments to growth (financing/infrastructure (hardware and software), literacy and mindset of patients and doctors).

Thinking about an area like BBR (Mpumalanga), what are some of the main structural issues in the rural areas, preventing the implementation of e/m-Health?

'The National Health Insurance' document discusses the 'harnessing of cost-effective technology but how this raises the cost of services'. What are the ways around this?

Political empowerment needs to be accompanied by cultural and organisational change within government institutions themselves. Therefore would you agree that therefore the same would have to apply to the e-Health landscape – a cultural

shift would be needed from within the health system, for example a nurse's attitude to the uptake of ICT?

How does government policy relate to/work alongside the ICT provider market in SA?

Future of e/m-Health

Given that ICT can exacerbate the existing socio-economic inequalities - what measures are/could be in place to deal with the current landscape/environment to enable South Africa to move forward (considering SA is a Middle Income Country and not a LMIC)?

Can we explore the potential future use of digital and networked technologies (e/m-Health) for the health system by health professionals and patients in rural South Africa? What is your take on this?

I am intrigued as to what new policies will be coming out/published in the next few months/years that you can comment on at this stage?

Will the newly elected President in May, mean that some of the NDoH policies are likely to change/dropped/altered/renewed? Which ones and in what way?

Can you pre-empt any other possible changes that may occur after the new government is elected next week?

What is Minister of Health, Dr Aaron Motsoaledi's vision for e/m-Health in SA?

Phase 8) eHealth and mHealth experts

As above.

Appendix 11: Final results table of Vutivi study

This table presents the overarching themes, evidence of findings, consequence and recommendation (Table version of final model in Chapter 8)

Overarching theme/Issue	Key Examples	Evidence of finding	Barrier/Benefit	High-level Recommendation
Accessible digital health information for patients and health-workers	1). Access to health Information 2). Web literacy of patients and health-workers	The need to widen a patient's health network to access health information from different channels. The need for health-workers to advertise an evidence-based digital resource that patients and themselves can access valid information.	Those with access to the Internet, usually via their phones have intermittent airtime credit available restricting the use of the website to certain periods. Mobile accessed information can be shared within the community verbally or digitally. Dis-benefit of this is to potentially marginalise those further who do not yet have access to the Internet.	Evidence-based website run by the NDOH using other LIMICs health websites as a template. Public health campaigns driven through messaging services. Training of health-workers, teachers and community leaders in particular in Internet safety.
Street-level bureaucrat Patient self-management	4). Phones used to support chronic disease management 5). Nurses use of computers 8). Digital solution to drug stock-outs	Patient self-management (health activities using phones/technology) Patients have their own informal mHealth	Implication of this - Reminder systems may not be beneficial to chronic patients who have been on treatment for long durations. Cost to the health system and health-worker time	Robust mHealth reminder system to strengthen the therapeutic alliance by digitally connecting the patient to the health system to increase adherence.

Health workers eHealth and mHealth use	11). Future use of eHealth and mHealth	<p>system to remind them to take medication and attend appointment using their phones.</p> <p>Health workers eHealth and mHealth use Nurses want to learn computer skills.</p> <p>Logistically using faxed order sheet errors create drug stock-outs.</p>	<p>implications of home monitoring system. Potential to use a mobile monitoring system increases social connectedness and motivation.</p> <p>Ramifications for nurses using computers not all will be willing to adopt technology in their workplace. Computer use will take time to become normalised as everyday practice. Supervisors will have to be trained with adequate support. Nurses to order drugs on a digital system relies on steady connectivity.</p> <p>SMS sent to patients when drug-stock are low.</p>	<p>Student nurses to receive computer training during their degree. Nurses trained in batches as to not disrupt the running of the clinic.</p> <p>Encourage patients and health-workers to use Stop stock-outs.</p>
Local opportunistic	6). Phones used to support doctors' work practices	Shift in the nature of how health-workers	A change in the ways personal devices are being used in the	Standardisation of digital work practices. Could make work practices

implementation of the use of eHealth and mHealth	<p>7). Local digital innovation by doctors</p>	<p>are using their phones in the work place. Localised adaption and adaption</p>	<p>work place by doctors in particular to enhance their work practices. Their technology use is intensified. Photographs taken and sent via WhatsApp create ‘evidence’. Consequence of this, if exposure and ownership of smartphones, more efficient work practices, more advantaged, greater opportunity to locally innovate to improve health work practices. Locally designed innovations have to fit into the health system current practices and help to mediate change.</p>	<p>commensurable but only if all doctors start using mobile systems for referrals/diagnostic reassurance.</p>
	<p>3). Adolescent phone use (informal)</p>	<p>Health workers – local innovation by doctors</p> <p>Patient informal use (non-health system recommended) for example searching the Internet, online health forums, private scans. Adolescents using their social networks to utilise healthcare.</p>	<p>Digital social media can increase a persons’ social networks but certain digital skills are needed. Digitally access can distract from school work and be an arena for gossip particularly around HIV.</p>	<p>DNOH and stakeholders speak directly to doctors about their innovative ideas because they know what the problems are and are trying to resolve them digitally.</p> <p>B-Wise Youth app is connected to an evidence based website.</p>

Management of resources and maintenance of equipment	14). Barriers to e/mHealth	Management at both the primary and district levels need to improve in terms of resources and maintenance strategies for equipment.	<p>The way in which current resources are maintained will have a counteractive affect on e/mHealth adoption.</p> <p>Dis-benefit is it may affect longevity of e/mHealth solutions</p>	ICT investment will only be effective if facility management improves otherwise the benefits of enhanced communication will curtail benefits and waste valuable resources such as computers and connectivity in clinics. Greater buy-in by managers of e/mHealth and better understanding of need to improve current systems. Informed maintenance strategies with back-up plan.
Health system dimensions	10). Landscape of e/mHealth in South Africa 12). Policy environment 13.) Health system dimensions 15.) Policy debate	<p>e/mHealth budgets are currently not financial stable because of reliance on external funders.</p> <p>The usability, sustainability and integration of the e/mHealth technology are going to be the government's greatest challenges.</p>	<p>e/mHealth strategies indicate policy direction and long-term investment. Advisory Committees and task teams including external stakeholders suggest greater commitment and knowledge sharing with NGOs and private companies. The consequence of this is improved understanding and evidence.</p>	<p>To keep laying the foundations of the NHI by scaling up e/mHealth but only to extend what it is financially viable when donors retract.</p> <p>Greater legislation and regulation through the HPCSA for doctors using messaging platforms such as WhatsApp or replace with more formalised system.</p>

			Although mHealth projects and DHIS are currently donor funded, if successful to improving health outcomes, treasury may increase budgets.	
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Appendix 12: Contribution to South African government policies resulting from the Vutivi study's research findings

Comments on the mHealth Strategy

From the main results, comments given towards the content of the mHealth Strategy were based on the findings from the Vutivi qualitative interviews with all participant groups. The points given will be considered in terms of implications and recommendations for government and other stakeholders in the discussion in Chapter 8.

Table 1. Comments given to the NDOH in 2014 to advise the content of the mHealth Strategy

Comments
There were very low levels of computer literacy amongst nurses, yet high levels of affordable smart phone use. Therefore computer training at the student nurse level or when nurses have to continue training to become a nurse on the next tier (e.g. junior to auxiliary to professional) may be beneficial, so that digital communications and eLearning becomes normalised from the onset. Ref. p. 17*: Capacity building for existing staff using mLearning
Any mHealth platform needs to be integrated into the usual systems that the end-users: patient/client are already or normally using.
The findings suggest that many patients were using social media such as WhatsApp and Mxit regularly or intermittently and perhaps forms of communications can be channelled through these mediums not just SMS depending on the target audience. Ref. p. 21: especially utilizing social media to reach adolescents
However the availability/affordability of airtime is fundamental to the person's type of phone use. For example, it was a reoccurring scenario that people would only buy between R5-R20 airtime (on any network provider) at any given time. Once that had run out, it would be between 3-5 days before they were able to purchase more airtime or for some until the next social grant payment date (for various SES/circumstantial reasons). Therefore adolescents using social media may be temporarily constrained in the absence of airtime causing intermittent use/response.

Non-clinicians (even clinical associates) can become X-ray technicians because clinical expertise is not needed to conduct an X-rays if remote diagnosis is the aim, whereas digital imaging using antenatal ultrasound would require a highly skilled clinician.

Ref: p 22. Ideally this would include mobile digital X-ray or obstetric ultrasound modality and training for nurses at the primary care level

The findings suggest that patients are already actively using their cell phones to help manage their chronic conditions, for example setting a reminder/alarm on their phone. Most patients said they would like to receive SMS reminders to complement their current method of remembering to take medication/come to their clinic appointment. Also phone-sharing, although not as highly-common as perhaps previous years, can be considered when sending messages to phones where other people may have access to the owner's phone e.g. such as grandchildren who check their grandmother's phone for her, in case the content is private and confidential.

Ref. p 23. SMS reminders: Take medication/attend clinic for screening programme/keep scheduled appointments/target behaviour change

It was found that nurses are in fact using Google to access health information on their own cell phones in the work place but few had personal email accounts. Also, rural doctors could access patient blood results using their personal cell phones if they had purchased data to access Trackcare (National Laboratories web system). Although this process was self-initiated.

Ref. p. 23 Managers access their email via cell-phone and other mobile devices

- *The page numbers refer to the mHealth Strategy pages.*
- **Comments on the NHI White paper**



Draft notes for Peter Benjamin – 10th February 2016

Comments for input into the NHI White Paper from Jocelyn Anstey Watkins

In response to what is needed to gain a functional information system -

South African primary healthcare can be strengthened using eHealth and mHealth by:

-Training of health workers in ICT

Although the Ideal Clinic and NHI pilot are training a subset of nurses, this needs to include:

The training of student nurses in ICT skills ready for the workplace. This needs to be normalised within their work labour. 'Digital labour' as a means of improving work efficiency, be this for the recording data (digital registries), searching for health information on a secure digital online resource (ideally a Department of Health website for both health workers and patients to access to include digital health guidelines and a symptom checker) or tracking blood test results online.

This type of recommended website could link to the DOH apps already published in the public domain such as the PHC Clinical guidelines app and other mHealth services such as MomConnect and B-Wise. This would improve the validity of digital information retrieved by health workers and patients. This resource is much needed with the uptake of smart phone devices and people seeking medical information online, which can be to their detriment if the retrieved information is falsified.

More clinic and community free Wi-Fi hotspots would promote the ability to use this website. This will increase the digital channels of communication (Mobile web/SMS) to reach UHC goals faster. People can therefore navigate across different mHealth platforms to access health information, which may improve health education and in time health outcomes.

Also, the endorsement of digital up-skilling of nurses will be beneficial for work practices especially those unfamiliar with paper-based methods.

We should support the use of informal mHealth particularly using cell phones by nurses and doctors who are creating/adopting communication services to meet their works needs. Local self-initiated innovation can improve the health of people and work practices. There is the possibility for some of these ad-hoc services, which are proving beneficial, to be scaled-up. For example the use of a secure messaging system between doctors to improve patient referrals.

-Services that could be offered (e.g. mobile ultrasound)

When nurses have relevant ICT skills, further training in obstetric ultrasonography using a mobile ultrasound device may be beneficial in reducing referrals to the district hospital and improve antenatal services at the PHC level for high-risk pregnancies. Ultrasound images could then be digitally sent to a doctor/specialist at the hospital for further examination/remote diagnosis using a telemedicine service. Research has found that many rural women are seeking and paying for private ultrasound services. This may be linked to social status. This is placing a burden on the public health system for those women who cannot afford to pay for

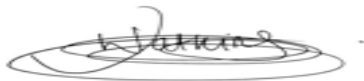
private scan. If obstetric ultrasound becomes part of routine antenatal services at the PHC level this could aid the personalisation of the pregnancy experience.

Additionally, the management of any new technology must be considered with maintenance strategies in place before implementation and managers taking responsibility for eHealth technology. Health workers and managers alike must understand the usefulness of eHealth and mHealth technologies if they are to aid improvements in health outcomes and work flow. The strengthening of rural hospital management can include how the management will also adopt eHealth as part of their core infrastructure.

The rollout of the NHI, will increase health worker's role in providing policies to the people.

In addition, I include a diagram from my recent thesis, which visually displays the aforementioned comments.

Thank you.



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Appendix 13: Description of paper patient files (Chapter 5)

- Files are kept in a store and listed in alphabetical order. However since many Shangaan surnames start with the letters 'M' or 'S', the ordering system does not work because there are only two places to search.
- Paper files were often tatty and the demographic information on the front of the file is hand written, sometimes illegible.
- Some files had a coloured sticker on the front to indicate the patient's ailment category. This colour aligns with the coloured footprints stuck on the floor as to which queue they wait in.

- Patient files are often lost and the waiting time for files just to be retrieved can be up to three-hours thus delaying accessing healthcare every time the patients come to consult.
- During hospital observations the data clerk from the maternity ward showed us the derelict building that housed the patient files in large boxes.

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Photo 25. Mama Matlala outside of her home (January, 2016)

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